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Evaluating models of care closer to home for children and young people who are ill: a systematic review

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Glossary of terms/abbreviations

ADHD	Attention deficit hyperactivity disorder
A&E	Accident and emergency department
ALL	Acute lymphoblastic leukaemia
ANCOVA	Analysis of co-variance
CCHCC	Coordinating Centre for Home and Community Care
CCN	Children's community nurse
CCNT	Children's community nursing team
CCTH	Care closer to home
CIPFA	Chartered Institute of Public Finance and Accountancy
CT	Commuted tomography
CVC	Central venous catheter
DGH	District general hospital
ED	Emergency department
EPOC	Cohrane Effective Practice and Organisation of Care Group
FEF_{25-75}	Forced expiratory flow between 25% and 75% of FVC
FEF_{max}	Forced expiratory flow at maximum effort
FEV_1	Forced expiratory volume
FVC	Forced vital capacity
GP	General practitioner (family doctor)
HaH	Hospital at home
HbA_1	Glycated haemoglobin
HbA_{1c}	Glycosylated haemoglobin
HNH	Home nocturnal haemodialysis
HOT	Home oxygen therapy
HPN	Home parenteral nutrition
ICU	Intensive care unit
IDDM	Insulin dependent diabetes mellitus
IV	Intravenous therapy
LOS	Length of stay
LPD	Legg Perthes Disease

MEI	Mannheim Parent Interview
NICU	Neonatal intensive care unit
NSF	National Service Framework
O^2	Oxygen
OR	Odds ratio
PAIS	Psychological Adjustments to Illness Scale
PDSN	Paediatric diabetes specialist nurse
PHC	Paediatric home care
PRBC	Packed red blood cells
QoL	Quality of life
RCN	Royal College of Nursing
RCT	Randomised controlled trial
RSCN	Registered sick children's nurse
SD	Standard deviation
SEM	Standard error of the mean
SF-36	Short Form (36) Quality of Life measure
TBI	Traumatic brain injury
THC	Telehome care
TPN	Total parenteral nutrition
VAS	Visual analogue scale
WISC	Wechsler Intelligence Scale for Children

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Contribution of authors to the systematic review

Professor Gillian Parker (Director, SPRU) developed and wrote the original proposal, managed and directed all stages of the project, advised on methods and all stages of analysis, conducted the analysis for the trials and other comparative studies for the systematic review, and co-wrote and edited this report.

Ms Gemma Spiers (Research Fellow, SPRU) was a member of the systematic review team, conducted the initial analysis for the other comparative and descriptive studies in the systematic review, and co-wrote this report.

Dr Karl Atkin (Professor, Department of Health Sciences) was a member of the systematic review team involved in selection of papers and data extraction, and commented on this report.

Dr Yvonne Birks (Senior Research Fellow, Department of Health Sciences) was a member of the systematic review team involved in selection of papers and data extraction, and commented on this report.

Karin Lowson (York Health Economics Consortium) undertook the analysis for the health economics component of the project and co-wrote chapter 8 and the health economics chapter in this report.

Kate Light (Information Specialist, Centre for Reviews and Dissemination) was a member of the systematic review team, and developed and carried out the searches for the review.

Executive Summary

Background

Standard Six of the National Service Framework for Children, Young People and Maternity Services established a vision for the future of services for children and young people who are ill. At its broadest, this requires providing timely, high quality and effective care, as close to home as possible, within a locally co-ordinated system of health, social care and education, and that meets individual needs. Achieving this vision will require substantial development and change in existing patterns of services. The aim of care closer to home (CCTH) for children has been articulated repeatedly since the 1950s, in policy documents, by campaigners and professionals, but progress has been slow. One impediment to progress appears to have been the evidence base to support development.

A systematic review of paediatric home care in 2000 (Parker *et al*., 2000) found no completed, controlled evaluation of any form of generic children's community nursing services in the UK, and the evidence base was weak in relation to specialist provision, too. Further, while descriptive accounts of service developments often contain detail of the benefits and challenges of establishing a new model of care, this material has not been synthesised to provide insight into broader organisational issues around providing CCTH.

Aims

1. To update and extend a systematic review, to identify recent evidence on effectiveness and costs of CCTH for children with long-term conditions, and extend the review to CCTH for children with short-term health needs.
2. To review the descriptive literature on CCTH in the UK, focussing particularly on service delivery and organisational issues.

Methods

The systematic review followed the original review strategy, following Centre for Reviews and Dissemination guidelines, but with different inclusion criteria in order to review evidence on CCTH for children with short-term health needs. As well as updating international evaluative evidence, descriptive evidence for models of CCTH provided in the UK was also reviewed. Searches covered the period 1990 to 2007. Analysis was narrative and reported in four sections, depending on the methods of the primary research: RCTs, other comparative studies; studies including some health economics data; and descriptive accounts of UK-based services. A 'best evidence' approach was used, with no study excluded because of its quality.

Results

Some 16,570 unique publications were identified. Eleven RCTs (16 papers), 26 other comparative studies (34 papers), 20 papers including health economics data, and 45 accounts of UK services (63 papers) were included and reviewed.

Evidence from RCTs

One new trial of supported early discharge for low birth weight or medically fragile babies suggests a degree of cost effectiveness, with fewer days of hospital care and improved weight gain, coupled with equivalent costs for both groups. The studies in the earlier review showed no differences in clinical outcomes but apparently reduced costs. There was no assessment of impact of or the costs of care for family members in the new study.

One new trial of home care for children with newly diagnosed diabetes was included. This reported equivalent outcomes for children treated in hospital or in 'outpatient' settings. We were unable to obtain detailed results for this trial, which was reported only as a conference abstract.

Two new studies of home care for children with mental health problems suggested equivalent clinical and social outcomes for CCTH and in-patient care and similar levels of impact on family or carers. Neither trial addressed costs, nor did they explore children's or their families' satisfaction with care.

The previous review did not cover home care for acute physical conditions that were likely to resolve. The focus in the current review was on CCTH compared to ongoing hospital care or to a return to hospital for treatment after a period of home care. Three RCTs were identified. In two, where children were discharged home rather than admitted to hospital, there were overall higher days of care, including readmissions. Other clinical outcomes were largely equivalent, although one trial suggested a higher level of complications in CCTH. Two trials examined family costs and both suggested a reduction for families using CCTH. All three trials found that parents and families were happy with CCTH and likely to choose it as an option if the need arose again. Only one trial reported health costs. CCTH costs were higher overall than hospital costs, but the CCTH scheme had not run at full capacity during the trial. The health economists involved with the trial thus suggested that it was not possible to come to firm conclusions about the relative costs of CCTH compared to hospital care.

There was no RCT of home chemotherapy in the earlier review. A crossover RCT was identified for the current review that demonstrated quality of life gains for children with the home chemotherapy regime, while the costs of care over and above the chemotherapy were equivalent.

The earlier review did not include CCTH which delivered interventions in children's homes rather than in clinic settings. Two RCTs were included in the current review. A study of treatment for chronic headaches showed a mixed pattern of change over time on clinical and psychological outcomes for the two treatment groups. The authors claimed that home-based

treatment was 'cost-effective', based on mean percentage change in the main clinical outcome (headache index score) per hour of therapist time. A trial of rehabilitation for traumatic brain injury suggested improved clinical and mental functioning outcomes for children treated at home compared to in a clinic. No costs data were reported.

A single RCT of telemedicine to support the families of children discharged from hospital with complex congenital heart disease was included. The reporting of the outcomes in the published papers makes it difficult to come to any conclusion about the costs or effectiveness of the service.

Evidence from other comparative studies

The review of other types of comparative studies showed that the range of CCTH services being evaluated has increased since the earlier review. The type and range of evidence reported included both costs and quality of life outcomes, but clinical effectiveness outcomes were notable by their absence in most studies.

Despite this growth in the evidence base, quality issues made it difficult to establish its robustness.

There was no clear consensus from other comparative studies about CCTH or its comparator. Evidence largely suggested that CCTH was no less effective clinically or more costly than routine care. This was particularly the case for home care for mental health problems, technological care at home, and early discharge schemes, both to home and outpatient settings. Not all studies considered quality of life outcomes but, when they did, some evidence favoured CCTH.

Evidence from studies including health economics data

All but two studies reviewed appeared to show savings associated with CCTH. In some cases, these savings were to health services alone, in others to society more generally. While there are quality caveats to be applied to some studies, the overall conclusion is that the health economic argument for CCTH is becoming stronger, and is certainly much stronger than it was when the original review was carried out. However, economic benefits of CCTH seem to be sensitive to the complexity of the needs of the children, to the skill mix of CCTH teams and to the stage of development both of the model of care itself and of the local health economy. Where economic benefits were not evident, this was apparently due to early evaluation, when services were not running at full capacity or when there had been no linked disinvestment in acute care.

Evidence from descriptive UK studies

The evidence here indicates that that are three 'dimensions' to how CCTH is modelled: home-based or hospital-based; generic or condition specific; and short term or long term. These dimensions are reflected in skill mix and in the complexity of service delivery and organisational characteristics.

Despite the key role of primary care when CCTH is delivered in the community, few descriptive accounts discuss the implications for primary care.

Although these accounts offer some insight into CCTH services, service delivery and organisational characteristics were not often described in any detail or in a way that would allow health service managers to understand contextual issues that might be important if they wanted to set up CCTH services in their area.

Conclusions

The evidence base related to CCTH has not grown substantially since the previous review, but this updated review has added weight to the conclusion that models of CCTH do not deliver poorer clinical outcomes for children; neither, overall, do they impose a greater burden on families. Indeed, in some cases, there is evidence of reduced burden and costs for families. There is also growing evidence, albeit based on weaker evidence, that CCTH may reduce costs for health services, particularly for children with the most complex and long-term needs. However, skill mix and the ability to deliver cost reductions in other parts of the local health economy influence cost reductions. Descriptive accounts of CCTH in the UK are disappointingly vague on the service delivery and organisational features of the services, giving little guide to best practice.

1 Introduction

This report is an updated and extended systematic review of international evidence on services that provide care 'close to home' for children and young people who are ill. The review was part of a larger project to support the implementation of the National Service Framework (NSF) for Children, Young People and Maternity Services (Department of Health and Department for Education and Skills, 2004) which has been published separately (Parker *et al*., 2010). This report provides full details about how the review was conducted and about its detailed findings.

Standard 6 of the National Service Framework for Children, Young People and Maternity Services has established a vision for the future of services for children and young people who are ill. At its broadest, this requires providing timely, high quality and effective care, as close to home as possible, within a locally co-ordinated system of health, social care and education, and that meets individual needs. While few would dispute this vision as an aim, attaining it will require substantial development and change in existing patterns of children's and young people's services.

The aim of care closer to home for children and young people who are ill has been articulated repeatedly since the 1950s, in policy documents, by campaigners and professionals, but progress has been slow. The House of Commons Health Select Committee (1997) reported that by 1981 there were only eight teams of community children's nurses (CCNs), designed to support sick children at home, in the UK. By 1991 this had risen to 159 and to 186 by 1993 (Lessing and Tatman, 1991; Tatman and Woodroffe, 1993). Royal College of Nursing (RCN) figures from 2006 listed 234 teams across the UK, 183 of which were in England (Whiting, 2007). At the same time, there has been an increase in community paediatric nursing activity, with initial episodes of care growing from 23,300 per year to 42,600 between 1993 and 2003 (National Statistics, 2004). Despite this growth, there is still considerable geographical variation in provision. In 1993 only 30 per cent of children had access to a 'generic' CCN team in their district (Tatman and Woodroffe, 1993). Preliminary analysis of RCN figures, carried out by our team before this project started, shows continuing variation. The number of 'children per team' varied from around 30,000 to 125,000 in different strategic health authorities (SHAs), and there seemed to be a gradient in provision that largely followed levels of deprivation.

As well as geographical variation, teams and what they provide also differ. They can be community- or hospital-based, provide specialist or generic care, and acute or longer-term care. However, many are hybrids and cover both specialist and generic needs, over both the short and longer term (Parker et al., 2002). Some aim to prevent acute hospital admission (Sartain *et al*., 2002) while others have a wider remit in relation to prevention of admission, early discharge and support of children with long-term health care needs. Other variation in service delivery and organisation

is evident (Eaton, 2000; While and Dyson, 2000). Some teams provide 24-hour care or cover, others provide care late into the evening but not over night, some provide care only during 'office hours'. The skill mix, seniority, qualifications and sizes of the teams also differ from team to team.

The overwhelming impression, as stated in the evidence reviewed for the NSF (Department of Health, 2005), is of development 'according to local need and circumstance rather than an evidence-base of the most effective model of provision' (p.26). The House of Commons Select Committee (1997) highlighted this issue when it recommended that the Department of Health should monitor the effectiveness of local models and structures, so that improved advice and guidance could be given to providers. However, while there is a UK literature on the development of care closer to home for children and young people who are ill, it has weaknesses in relation to informing policy and provision.

First, little of the literature is evaluative. A systematic review of paediatric home care that we carried out in 2000 (Parker *et al*., 2002) found no completed, controlled evaluation of any form of generic CCN services in the UK, although one randomised controlled trial (RCT) has been completed since. The evidence base is weak in the realm of specialist provision, too. For example, while home-based support for children with long-standing conditions such as diabetes or asthma is increasingly popular, 'there seems relatively little evidence to suggest whether or not it improves outcomes or reduces costs, for children themselves, their families or the health service' (Parker *et al*., 2002: 71-72). The same is largely true of home-based, high technology care for children with the most complex care needs.

The second weakness is that the views of children and young people and their families are not central in much of the literature. The evidence review for Standard 6 of the NSF (Department of Health, 2005) stated that, despite the lack of evidence on clinical or cost effectiveness, 'home care is preferred by many families' (p.126). Yet, controlled studies rarely report the views of families, and even less those of children or young people.

Thirdly, descriptive accounts of individual service developments often contain detail of the benefits and challenges of establishing a new model of care. However, this material has never been synthesised to provide insight into broader organisational issues around providing care closer to home.

A Department of Health research initiative to generate evidence to inform implementation of the NSF recognised the need to strengthen the evidence-base in relation to services that provide care closer to home for children and young people who are ill. Our work was a response to that need and tackled the three weaknesses outlined above. It offers a multi-faceted study, using mixed methods, to generate new understanding and to make best use of already available material in order to inform the development of innovatory practice in models of care closer to home. This systematic review was a key part of the work and influenced other elements of the main study.

1.1 Definitions

In defining the scope of the overall study, various issues emerged.

First, which children are acutely ill or with a long-term condition that is not disabling? Those who are ill may or may not have needs that continue beyond an initial period of acute illness. Those who have complex, long-term needs or who are disabled may experience periods of acute illness that has nothing or little to do with their underlying condition. Some will have needs for treatment over a longer period – for example, home chemotherapy or oxygen – that will eventually lead to restored health. Children with some long-term conditions – sickle cell disorder, for example – may be unaffected for much of the time yet need intense inputs of acute care during crises.

Secondly, there are issues about the definition of CCN services. The Royal College of Nursing maintains a directory of CCN services and uses CCN 'as a generic term to include community paediatric community nurses and children's home care nurses' (RCN website). This inevitably raises questions. Are teams containing staff other than children's nurses CCN teams? Is a 'home nursing team' (Cramp *et al.*, 2003) the same as a CCN service? Do specialist nurses who provide outreach into the community from secondary care settings constitute a CCN team? Is an acute 'hospital at home' team that includes continuing paediatric consultant oversight a CCN service?

Thirdly, how do we define services that provide care as close to home as possible? While the term seems to suggest community-based provision, some hospital services also allow children to be cared for at home. Paediatric ambulatory care – for example, short-stay units and emergency-assessment units (Ogilvie, 2005) – may prevent overnight stays or enable early discharge.

Finally, there is the issue of function – what are services that provide care close to home actually set up to do? Some have a single function – for example, preventing acute hospital admission for short-term ill health; others have multiple functions – for example, admission avoidance, early discharge, *and* long-term support in the community. This definitional issue is similar to that encountered in studying the development of models of intermediate care for older people (Parker *et al.*, 1999). The strategy taken in that work was to define services in terms of their primary or predominant *function* and then describe the delivery and organisational features of services that served that function.

These definitional issues ran throughout and influenced the conduct of this review.

1.2 Updating and extending the original review

The first ever, systematic review of paediatric home care (PHC) was funded by the NHS Health Technology Assessment R&D Programme in 1998 and led by the principal investigator in the review reported here. The original review

was international in scope and covered research from 1985 to July 2000. It included evidence from randomised controlled trials (RCTs), other comparative studies, and studies that involved some form of health economics or service costing.

The review focused on children with complex, acute or long-term illness, where home care was an alternative to hospital admission or prolonged hospital care. It thus excluded out-patient care, models of care limited to training or education about a medical condition, and home care for conditions unlikely to have long-term consequences (e.g. post-appendectomy care, simple fractures, gastroenteritis).

The updated review was intended to capture evaluative research on home care for children that had taken place since 2000. However, policy interest in models of care that might divert children and young people from acute hospital care had developed in the interim, as suggested by the NSF. We therefore proposed extending the scope of the review by including RCTs, other comparative and costing evidence on PHC both for conditions unlikely to have long-term consequences and for palliative care need. We were also aware from our experience in the previous review that there was a very large descriptive literature on models of home care that could be reviewed to provide insight into the services delivery and organisational features of services. We therefore also proposed to review systematically the descriptive literature that we identified through our searches. Because of the different contexts within which services are funded, delivered and managed in different countries, we decided to limit this part of the review to literature describing UK services. All other parts of the review used international literature.

1.3 Structure of the report

In Chapter 2 we describe the methods we used to carry out the review and in Chapter 3 report the findings from the randomised controlled trials that we identified. Chapter 4 turns to findings from studies that adopted other types of comparative designs, while Chapter 5 reports the findings of the descriptive element of the review. The findings of the health economics element of the review are in Chapter 6 and Chapter 7 concludes the report by integrating findings from across all elements of the review. Appendices include full bibliographical details of the papers reviewed in each section.

2 Review methods for comparative and descriptive studies

As the purpose of this review was to update a previous review on paediatric home care (Parker *et al*., 2002), broadly the same methods were used here. However, while the previous review focused on evidence concerning children with long-term or acute illness, this review was extended to incorporate evidence on postsurgical home care and children with palliative care needs. Because of this extended scope, the methods were adapted accordingly, in relation to the search strategies used and the criteria for inclusion and exclusion. This is discussed in further detail below.

2.1 Pre-scoping and scoping exercise

Pre-scoping and scoping exercises are initial stages of reviews that aim to quantify and identify the likely sources of relevant literature, outlining the parameters of what is available, and thereby informing the main search strategy. As this review's main aim was to update and to extend an existing systematic review, it was felt that a scoping exercise would provide little additional value.

2.2 Main search strategy

Comprehensive searches were carried out by the Centre for Reviews and Dissemination (KL) in April and May 2007. Twenty-one databases were searched covering both published and unpublished (or 'grey') literature. Full details of the search strategies and the databases are in Appendix 1. A total of 22,527 records was retrieved which, after de-duplicating, was reduced to 16,440 records. The databases searched and the number of hits retrieved from each is listed in Table 1. Searches covered the period from 1990 to 2007, to provide overlap with the earlier review.

2.3 Additional searching

The reference lists of all included papers and relevant review papers were searched for potentially relevant studies, which were then cross checked with the original searches. Twenty-three potentially relevant studies that had not previously been identified by the main searches were found. A further 19 studies were found via the reference lists of relevant review papers, giving 42 newly identified papers. Each new paper that was identified underwent the selection for relevance process (detailed below), and five were subsequently selected. One of these papers proved untraceable, apparently due to inaccurate referencing.[a] Late in the review

[a] Davies, C. and Dale, J. (2002) Paediatric home care for acute illness: I Impact on hospital services & costs, *Archives of Disease in Childhood*.

process, a systematic review of ambulatory paediatrics (Ogilvie, 2005) was identified. A total of 18 studies were identified as potentially relevant through this paper, of which six were selected for relevance. Table 2 summarises this information.

Table 1. Databases searched and number of hits retrieved

Databases searched	Number of hits retrieved
MEDLINE	5584
MEDLINE in process	72
British Nursing Index (BNI)	211
Cumulative Index to Nursing & Allied Health Literature (CINAHL)	3735
Health Management Information Consortium (HMIC)	394
The Cochrane Library	21
ASSIA	396
Social Services Abstracts	427
PsycINFO	2764
Science Citation Index (Expanded)	1688
Social Science Citation Index	1560
EMBASE	4207
ISI Proceedings – Science and Technology	237
Clinical Trials.gov	83
Social Care Online	382
DoH Point	83
CenterWatch	38
Dissertation Abstracts	47
Index to Theses	35
National Research Register	401
Current Controlled Trials	162

Table 2. Papers identified through hand searching

Identification of other papers	Number of papers identified	Total selected for relevance
Papers identified via reference lists of included papers	23	3 (1 unobtainable)
Papers identified via reference lists of included review papers	19	2
Papers identified via other sources	18	6
Total	60	11 (1 unobtainable)

2.4 Inclusion and exclusion criteria

As highlighted in our earlier review, it is difficult to set firm criteria for the inclusion and exclusion of studies relating to this topic area, given the ambiguity about what constitutes paediatric home care. Since the last review, and even since the publication of the National Service Framework for Children, Young People and Maternity Services (DH/DfES, 2004), the concept of care closer to home has evolved in the policy literature, and the inclusion criteria for the review were revisited. For this review, papers were included using criteria based on the intervention/model of care being evaluated, conditions targeted by the intervention, and study design. These are discussed further below.

2.5 Model of care/ intervention

Any model of care that brings care closer to home (CCTH) by preventing immediate inpatient admission and/or reducing length of stay for children with acute, chronic, complex or palliative care needs was included. The model of care had to involve clinical care and the care had to be that which would be provided in a clinical setting, if the closer to home service was not available. This meant that educational or training interventions without a clinical component were not included. Longer-term prevention strategies to prevent or avoid hospital care – for example, interventions to reduce asthma triggers in children's homes - were also not included.

2.6 Conditions

In terms of criteria for specific conditions, the previous review focused on acute and chronic conditions and specifically excluded palliative care services, post-surgical home care and 'routine' home monitoring. The updated review was extended to incorporate models of home care for children with life threatening and life limiting illness and postsurgical care but not routine home monitoring. As in the original review, conditions that were not covered included developmental disability, non-organic failure to thrive, and child abuse.

2.7 Study design

For the comparative review studies were included only if a comparative design of some sort was used and, thus, if comparative data were reported. No exclusions were made based on study quality, and a best evidence approach (Petticrew and Roberts, 2006) was adopted. For the descriptive review, studies were included if they described a UK-based CCTH service.

The criteria for inclusion and exclusion are summarised in Table 3. These criteria were used to develop an algorithm to be used when selecting studies.

Table 3. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• Models of home-based care which prevent immediate admission to hospital • Models which provide care within the home rather than in hospital • Models which provide palliative care at home rather than in hospital • Any acute, chronic/complex, life threatening or life limiting illness • Children under 18 years • Published since 1990 **Study design for comparative review** • Randomised or pseudo-randomised trials • Studies with a health economics element • Non-RCT studies comparing home-based care against some other model **Study design for descriptive review** • Any study providing descriptive details of UK-based CCTH services	• 'Portage' type schemes • Job satisfaction studies • Parenting skills programmes • Child abuse and/or non-organic failure to thrive • Service standards • Normal child bearing/pregnancy • Studies comparing equipment use • Resettlement from long stay hospitals • Routine home monitoring • Model limited to education or training about a health condition • Papers included in previous review **Study design** • Letters/editorials/opinion pieces • Single person case studies • Foreign language studies unless an RCT

2.8 Selection for relevance

The first stage of selecting studies involved a process of selection based on the apparent relevance of a paper, determined by its title and, where available, its abstract. Reviewers worked independently initially to assess a paper's relevance, and then in pairs to reach agreement. When two reviewers failed to reach a consensus about the relevance of a paper, a third reviewer made the final decision. Once decisions were made about relevance, the full paper was retrieved. A total of 822 (726 from the electronic searches and 60 from the additional searches) papers were selected for relevance, 74 of which were unobtainable, and 32 of which were included in the previous review and therefore excluded.

2.9 Selection for inclusion

Once the full papers were retrieved, reviewers read the full paper and then worked in pairs to decide whether it should be included in the evaluative review and/or the descriptive review. A note was also made as to whether the paper had costing data so that it could be included in the health economics element of the review. Thirty-seven studies[b] (reported in 50 papers) were selected for inclusion into the evaluative review (see Figure

[b] 11 trials (reported in 16 papers) and 26 other comparative studies (reported in 34 papers).

1), 63 papers into the descriptive review, and 17 papers into the economics review. Table 4 summarises the record of selection for the main electronic search results, for the evaluative review, descriptive review and health economics review.

Table 4. Record of selection for electronic and additional searches combined

Number of papers identified in total	16,500
Number of papers selected for relevance	822
Number of papers unobtainable	74
Number of papers selected for inclusion and proceeding to data extraction for evaluative review	50
Number of papers selected for inclusion and proceeding to data extraction for descriptive review	63
Number of papers selected for inclusion and proceeding to data extraction for health economics review	17

2.10 Data extraction for comparative review

All papers included into the comparative review were designated as randomised controlled trials (RCTs), or as studies of 'other comparative design'. Eleven RCTs and 26 studies of another comparative design were included for data extraction.

Data from included studies were then extracted into an Excel spreadsheet. Each reviewer took responsibility for extracting data from an approximately equal number of papers, and each reviewer's data extraction was then double checked by a second reviewer. The quality of studies was assessed using both EPOC criteria and Jadad criteria (EPOC, 2002; Jadad, 1998) for the RCTs. None of the studies categorised as 'other comparative design' fitted into EPOC study design criteria and were therefore not formally assessed for quality. A discussion of the methodological limitations of these studies and the following implications is, however, included in Chapter 7.

Studies included in the comparative review were data extracted based on the following topic areas:

- Publication details
- Details of the model of care
- Sample and study details
- EPOC and Jadad quality assessment criteria
- Mortality
- Length of stay and readmission to hospital
- Clinical outcomes
- Physical outcomes
- Psychological outcomes
- Costs to the health service
- Costs to the family

- Impact on the family
- Impact on social life
- Impact on education
- Satisfaction with the service
- Knowledge of the condition.

A separate tool was used to extract studies with health economics data.

2.11 Data extraction for the descriptive review

Papers included in the descriptive review described a CCTH service delivered in the UK only (as opposed to the comparative review, which included international material as well). We included here any papers from the comparative review that had described UK-based services, as well as purely descriptive accounts. Publications describing general CCTH provision (e.g. Community Children's Nursing surveys, narrative accounts) were not included. Selected papers were divided into four categories: models of generic home care, models of condition specific home care, models of palliative care closer to home, and models of community based care. The latter category was broad, and was therefore further sub-categorised into Children's Community Nursing Teams (CCNTs), short stay units for acute conditions, day case care, short stay houses, and community therapy for mental health problems. Data extraction for the descriptive review intended to cover the following areas:

- Generic service delivery and organisation details (e.g. type of service, staffing, hours of operation)
- The users of the service
- The care closer to home activities in each service
- The conditions catered for in each service.

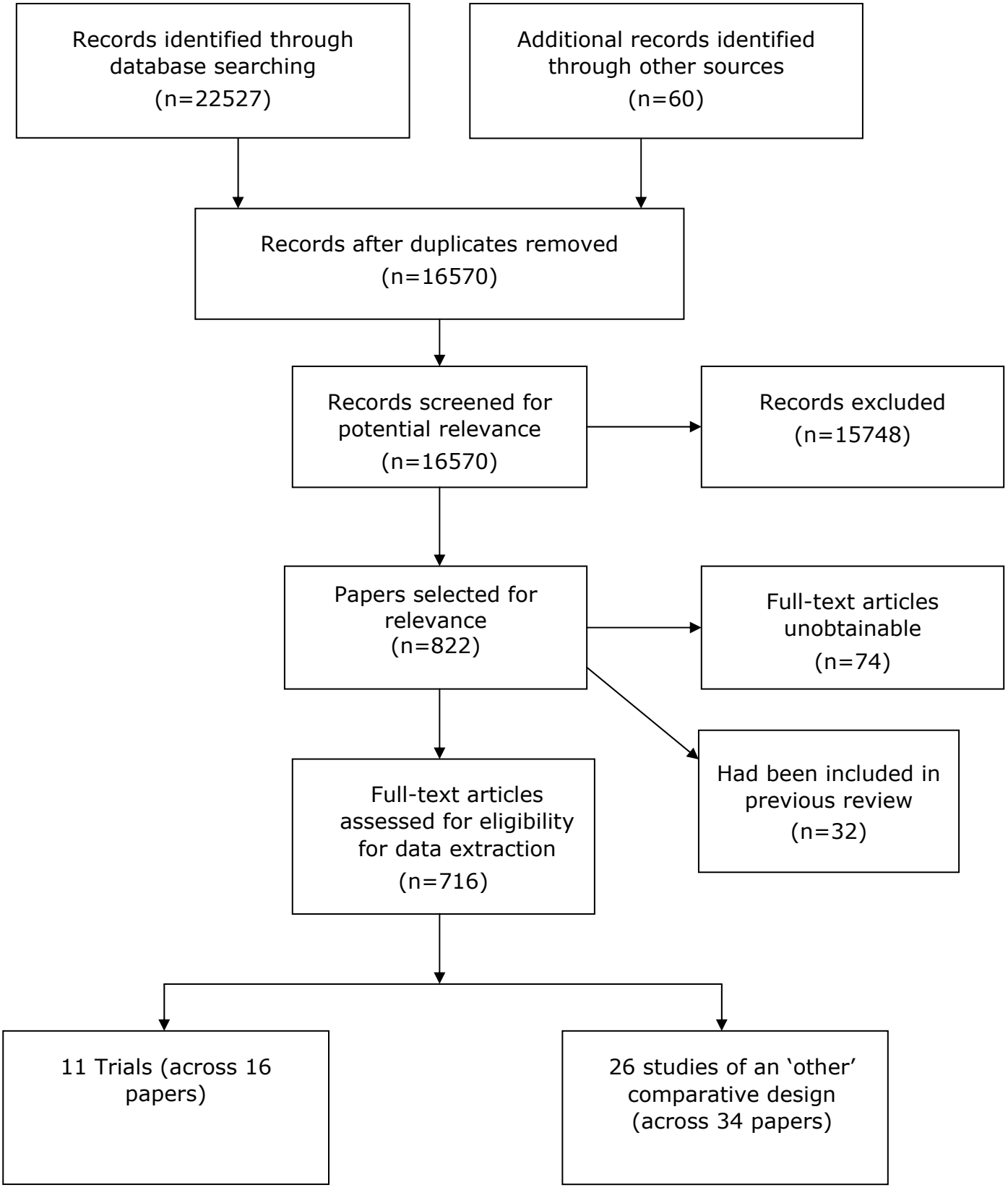
The majority of papers, however, did not provide sufficient details about the users of services, and thus it was not possible to include this information in the review.

As these papers were not reporting evaluative research, quality assessment was not performed. However, the papers varied considerably in how much information they reported, and in many cases, a service could not be described completely in terms of the topics covered in the data extraction form.

2.12 Analysis

The wide variation in the nature of care closer to home services in the comparative review and the lack of common outcomes reported across the studies means that there were no opportunities for quantitative meta-analysis based on these newly identified publications. Analysis is thus confined to narrative synthesis (Mays *et al*., 2005). The analytical approach taken in the descriptive review is wholly descriptive, as would be expected.

Figure 1. Flow chart showing search and selection process for comparative review



3 Trial results

In this chapter, we report findings from the randomised or pseudo-randomised controlled trials identified in the updating. These are reported in sections, depending on the focus of the model of care:

- home care for very low birth-weight or medically fragile babies (one trial);
- home-based treatment for chronic or long-term conditions (one trial);
- home-based treatment for mental health problems (two trials);
- home care for acute physical conditions (three trials reported in eight publications);
- home chemotherapy (one trial);
- home based alternative to clinic based care (two trials)
- telemedicine support (one trial).

For ease of reading, all papers are referred to here by their first author and date only. Full bibliographical details of all the papers associated with the trials are in Appendix 2 while only the main paper for each trial (where there is more than one) is referenced in a separate table in each subsection.

3.1 Home care for very low birth weight or medically fragile babies

One trial was included in this section (Gibson, 1998).

Table 5 gives publication details for the paper from the trial, referred to hereafter by the name of the first author. The trial was in the USA. The details of the model of care and that with which it was being compared are outlined in Table 6.

Table 5. Details of trials of home care for very low birth weight and/ or medically fragile babies

Authors and title of paper	Publication details	N subjects	N controls	Jadad score (max 3)	EPOC score (max 7)
Gibson *et al*. (1998) Accelerated discharge of low birth weight infants from neonatal intensive care: a randomized, controlled trial	Journal of Perinatology 1998: S17 – S23	51	49	1	5

Table 6. Details of model of home care for very low birth weight and/ or medically fragile babies

Author and year	Country	Condition	Model of care	Compared with	Primary setting	Secondary setting
Gibson 1998	USA	Low birth weight ≤ 1800g	Accelerated discharge with home-care follow-up by NICU-experienced nurse	Conventional discharge	Home	-

Among the 369 'preterm' babies delivered at the four hospitals during the study period, there were 23 deaths and 133 babies met exclusion criteria, leaving 213 (58%) who met the inclusion criteria. Of these, 122 (33% of the total preterm births and 57 per cent of those who were eligible) were enrolled in the study. The other 91 families (43%) declined to participate in the study, the main reasons being anxiety about the child's health or discomfort about the prospect of early discharge. A further 22 of the 122 enrolled babies moved into exclusion categories while in hospital and were removed from the study. It is not clear from the paper whether this was before or after randomisation, which took place when the babies were 'clinically stable'. Personal contact with the first author confirmed that these babies were excluded after randomisation. The reasons for exclusion were clinical or related to the willingness or ability of caregivers (Gibson, 2008, personal communication). Forty-nine babies remained in the conventional discharge group and 51 in the accelerated group.

3.1.1 Quality of the trial

The trial met one-third of the Jadad criteria and four out of six of the EPOC criteria. The main problems were the unclear description of the randomisation procedure and uncertainty about whether exclusion of 22 babies identified as eligible for the study was before or after randomisation (see above).

3.1.2 Outcomes reported

Data about mortality, length of hospital stay, duration of home care, health costs and weight gain were apparently collected from hospital records. Details of readmissions, emergency department visits and 'general health status' were collected from families monthly over a one year period after 'completion of home care services'. Data on medical and developmental status was provided by hospital follow-up clinics at 40 weeks, 6 months and 12 months corrected age.

3.1.3 Mortality

The paper reports one death in each group in the study, but it is not clear whether this was at final follow-up or earlier.

3.1.4 Length of hospital stay and readmission

Mean length of stay in hospital was reported as 33.18 days (SD 22.88) for the accelerated discharge group and 45.80 (SD 27.02) for the conventional discharge group. The difference between these is reported as significant, with a p value of 0.004, although the statistical result is not reported directly. It is not clear from the paper whether the figures relate to initial length of stay immediately after birth or to total length of stay over the follow-up period of 12 months. Contact with the first author clarified that the data were related to the initial length of stay (Gibson, 2008, personal communication).

The duration of home care is also reported: a mean of 17.7 days (SD 8.02) for the accelerated discharge group and 9.86 (SD 8.20) for the conventional discharge group. The difference is reported as significantly different ($p<.001$). Again, these data relate to days of home care only for the initial period of discharge after birth.

There were 15 acute hospital admissions in each group in the first six months after discharge, but no details are given about the length of stay during these admissions. No baby in either group was readmitted within 14 days of initial discharge. In addition, there were 27 emergency department visits in the conventional discharge group and 28 in the accelerated discharge group during the six months after discharge.

If the hospital days are added to days of home care, this gives a total 'length of stay' of 55.66 days for the conventional discharge group and 50.35 for the accelerated discharge group.

3.1.5 Clinical outcomes

Weight gain in grams per day between 1800 and 2000g was 28.74 (SD 8.58) for the accelerated discharge group and 24.34 (SD 8.69) for the conventional discharge group. This difference was reported as statistically significant ($p=.011$) although the statistical result is not reported directly. Mean number of days on oxygen was not significantly different between the two groups, although the accelerated group did have a lower mean (11.08 with a SD of 15.71, compared to 17.48 with a SD of 21.75). It is not clear over what period these data were collected, but it seems likely that they relate to the period in hospital. This suggests some difference, in favour of the accelerated discharge group, in initial health status. However, the large SD for the conventional discharge groups means that the difference in mean values does not reach statistical significance ($p=.230$).

3.1.6 Health care costs

Home care, physician and hospital charges were reported for both groups but, as with other outcomes, it is impossible to tell from the paper whether these charges relate to the full period of follow-up or to initial hospital stay and discharge period. Contact with the first author confirmed that they related only to the initial stay (Gibson 2008, personal communication). Table 7 shows the charges reported. Here we see, as might be expected, that the hospital and physician charges for the accelerated discharge group were significantly lower than for the conventional discharge group. As a corollary, the home care charges for the accelerated discharge group were higher than for the conventional discharge group. Taken together, the average total costs of care for the accelerated discharge group were significantly lower, although the average charge per day was not. However, it is difficult to understand over what period this charge per day was calculated. If the total charges are divided by the number of days of hospital plus home care, the result is not the same as the mean charge per day reported in the paper.

Table 7. Health care costs for accelerated and conventional discharge for low birth weight babies

Author and year	Type of health care cost	Incurred over what period?	Mean (SD) costs for controls	Mean (SD) costs for subjects	Statistical significance
Gibson 1998	Home care charges	Not clear	US$ 1154 (1748)	US$ 3838 (2388)	p<.001
	Physician charges	Not clear	US$ 14276 (11924)	US$ 11006 (10.752)	p=.033
	Hospital charges	Not clear	US$ 103622 (74787)	US$ 74222 (4622)	p=.012
	Total charges	Not clear	US$ 119052 (SD 85498)	US$ 89066 (73432)	p=.023
	Mean charges per day	Not clear	US$ 2515 (684)	US$ 2486 (706)	p=.598

3.1.7 Sub-group analyses

This study also reported sub-group analysis of all outcomes, concentrating on babies whose gestational age at birth had been 27 weeks or more. The rationale for this was to test whether the differences observed between the two groups were maintained when babies who had more serious problems and complications were excluded. Eighty-seven babies had been of 27 weeks or more gestational age at birth. Those in the accelerated group still had significantly fewer days in hospital and significantly more days of home care but the total days of 'supervised care' (which had not been reported separately for the total sample, see above) was reported as not different between the groups. This was also the case for total days on oxygen. The rate of weight gain from 1800 to 2000g was also no longer significantly

different. Hospital and home care charges were still significantly different between the two groups, in the direction expected, but there was no difference in physician charges. Total charges for the accelerated group were still significantly lower but, as with the larger group, mean charges per day were similar.

Because of this apparent relationship between gestational age and outcomes, linear regression was carried out to examine the separate and joint effects of gestational age and discharge group. Analyses were carried out separately for weight gain, hospital charges, physician charges and total charges. These showed that both gestational age and discharge group influenced weight gain but that there was no interaction between them. For health care charges, however, the apparent advantage for the accelerated discharge group disappeared once gestational age was taken into account; there was no significant interaction in any of the models considered.

3.2 Home care for children with diabetes

As in the original review, this was an area where it was difficult to define the models of care in which we were interested. This is because of the substantial overlap between programmes of education and training for diabetes with programmes that deliver some element of care **alongside** education and training. We adopted the same approach in the updated review as we had in the first: that we were interested only in models that offered some element of care in or closer to children's homes, with or without education or training.

Only one new trial was identified in this area, and this only in a conference abstract (Simell *et al*., 1995). Repeated attempts to contact the authors of the abstract to obtain additional details about the trial failed and we have been able to find no subsequent publication related to the trial. The trial was in Finland and compared children with newly diagnosed, insulin dependent diabetes mellitus (IDDM) who were treated on an outpatient basis[c] with those admitted to hospital. All the children were non-ketoacidotic. Details of the publication and study are in Table 8.

There are no details about the model of outpatient care in the abstract, although it does say that insulin treatment and the content of diabetes education were 'similar' in both groups.

3.2.1 Inclusion and exclusion criteria

No details are given about inclusion and exclusion criteria, although all children in the study were non-ketoacidotic.

[c] Due to a lack of details in the abstract, we were unable to clarify whether 'outpatient' included home care or not and thus we have retained the study in the review.

3.2.2 Quality of the trial

With so little detail about the trial included in the abstract it is difficult to judge the quality of the study. The 'scores' reported in Table 8 are thus the minimum that this study might have achieved.

Table 8. Details of trial of home care for children with diabetes

Authors and title of paper	Publication details	N subjects	N controls	Jadad score (max 3)	EPOC score (max 7)
Simell et al 1995 Randomized prospective trial of ambulatory treatment and one-week hospitalization of children with newly diagnosed IDDM	Diabetes: Pathogenesis and Treatment, 1995, V suppl: 162A	30	30	1	2

3.2.3 Outcomes reported

The only outcomes reported were clinical – mean HbA_{1c} and insulin dose.

3.2.4 Clinical outcomes

Table 9 reports the clinical outcomes from the study. These show that children's metabolic control and insulin doses changed over time in both groups (though in which direction is not clear) but that these outcomes were not affected by the way in which they received their initial care. Neither did their outcomes vary over time, depending on their initial care. At some unspecified point, children who had received their care in hospital were on significantly higher insulin doses than those who had received outpatient care.

Table 9. Clinical outcomes of trial of home care for newly-diagnosed IDDM

Author and year	How measured	Period of follow-up	Subjects	Controls	Reported statistical significance
Simell 1995	HbA_{1c}	Two years	Not reported	Not reported	P=.697, time and treatment interaction P=.866 treatment effect P<.001 time effect
	Insulin dose	Two years	Not reported	Not reported	P=.159 time and treatment interaction

					P=.179 treatment effect P<.001 time effect
	Mean HbA_{1c}	Two years	7.6%	7.9%	P=.442
	Daily insulin dose	Not clear	0.6 IU/kg/day	0.8 IU/kg/day	P=.037

3.3 Home care for children with mental health problems

Two new studies were identified in this section – Mattejat (2001) and Gleuckauf (2002). The first was based in Germany, and compared in-patient and home-based treatment for children and adolescents with severe psychiatric disorders. The second was in the USA and compared two types of home-based counselling (video and speakerphone) with 'office-based' counselling for teenagers living in rural areas who had epilepsy who were at risk of mental health problems. Table 10 reports details of the studies.

The Mattejat (2001) study was a follow-up of children and young people included in two previous randomised studies based in psychiatric services in different German towns. Details of the previous studies are available in German only, so were not retrieved for this review. The study reported here could be characterised as a form of meta-analysis. It brought together data on the longer-term outcomes of two studies 'undertaken independently' by doctoral students (p.1/72) but which addressed similar questions and were supervised by the same principal investigators. However, as there were differences in the design of the two studies, the authors report the findings separately and we follow this in our synthesis.

Table 10. Details of trials of home care for children and young people with mental health problems

Authors and title of paper	Publication details	N subjects	N controls	Jadad score (max 3)	EPOC score (max 7)
Mattejat et al 2001 Efficacy of inpatient and home treatment in psychiatrically disturbed children and adolescents. Follow-up assessment of the results of a controlled treatment study.	European Child and Adolescent Psychiatry, 10: 1/71-1/79	35 (at follow-up)	33 (at follow-up)	1	3
Glueckauf et al 2002 Videoconferencing-based family counseling (sic) for rural teenagers with epilepsy: phase 1 findings	Rehabilitation Psychology, 47: 49-72	14	8	2	1

3.3.1 Inclusion and exclusion criteria

The inclusion and exclusion criteria for the two trials reported in Mattejat (2001) are not reported in the paper but were said to be 'clearly defined' in the original studies. Overall, they were said to account for around ten to 15 per cent of in-patient cases. The diagnoses of children and young people who were followed up were said to resemble the original samples and included 11 per cent 'neuroses', 17 per cent enuresis and encopresis, 17 per cent anorexia and other eating disorders, 19 per cent conduct disorders, 27 per cent emotional disorders, and nine per cent ADHD.

For the Glueckauf (2002) study the inclusion criteria were:

- a medical diagnosis of generalised or partial seizure disorder
- aged 12 to 19 years
- presence of an 'at-risk' or problem behaviour as reported by family members, community referral sources or both
- a minimum of third grade reading comprehension
- a minimum of one parent or guardian living in the home or who had ten or more hours weekly contact with the young person.

At-risk behaviour was defined as those exhibiting one or more of the following:

- depressive affect (lowered mood persisting for four weeks and interfering with everyday function)
- suicidal ideation, gestures or both
- poor school performance, attendance or both
- social isolation (young person spends 75 per cent or more of their time alone)
- aggressive behaviour (verbally or physically abusive or both)
- lack of adherence to prescribed medical routines (does not take anticonvulsant medication at prescribed times 25 per cent or more during the week)
- sexual promiscuity
- alcohol or non-prescription drug use.

3.3.2 Quality of the trials

Mattejat (2001) reports very few details about the original trials and, as a result, the quality scores are low. Although 92 children had been studied in the original trials, only 68 (74%) of these were included at follow-up. The majority of those not followed-up (17) had refused to participate and the remaining seven were said to be 'unavailable'. The paper does report that assessment of outcomes was conducted blind to treatment group membership.

Glueckauf (2002) also contains little detail about the methods used to conduct the study, so quality scores are low. However, it is clear that outcomes were not assessed blind to the group into which children had been randomised, and reliability and validity were not reported for all the primary outcome measures used. This study used a waiting list control group, members of which appear to have been randomised to one of the two treatment conditions at the point at which the original treatment groups had completed six sessions of counselling. Four of the nine families originally randomised to the intervention (videoconferencing) had no digital service in the rural communities in which they lived and they received speakerphone counselling instead. This was also the case for an unspecified number of the waiting list control group.

3.3.3 Outcomes reported

Mattejat (2001) reported the number of the child's or young person's symptoms, using the Marburg Symptom Scale and a rating of their psychosocial competence (adaptation at school or work). There are no details in Mattejat (2001) about the reliability or validity of either of these measures. No other outcomes were reported in either paper. Other outcomes were collected in the individual trials reported in Mattejat (2001), but only those that were common to both were reported in the follow-up study.

Glueckauf (2002) reported aspects of family 'issues' and functioning and the child's or young person's social skills. The paper also reported adherence to treatment and the quality of the therapeutic alliance but these are not further analysed in our review.

3.3.4 Clinical outcomes

Results for the 68 children and young people who were followed-up for an average of 44 months (range 26m to 62m) after treatment are reported in Mattejat (2001) (see Table 11). The primary analysis carried out was descriptive and thus did not compare treatment modalities statistically but calculated effect sizes for each group from pre-treatment to post-treatment, from pre-treatment to follow-up, and from post-treatment to follow-up. Logistic regression analysis was then carried out to examine which factors influenced long-term outcome and whether there were any differences in outcome dependent on treatment group. The model included treatment modality, age, sex, and presenting symptoms and was applied to each centre separately. This showed no statistically significant difference in change in symptoms related to treatment, once the other variables had been taken into account. Analysis of the symptom score at follow-up, again, showed no significant difference between treatment modalities but did show that females were significantly more likely to be without symptoms at follow-up than were males.

Table 11. Clinical outcomes for model of home care for children with mental health problems

	Clinical outcomes				
Study	**How measured**	**Period of follow-up**	**Subjects**	**Controls**	**Reported statistical significance**
Mattejat 2001: Marburg trial	Mean (SD) Marburg Symptom Scale (0-22)	Before treatment	1.9 (1.1)	2.2 (1.5)	
		After treatment	0.2 (0.5)	0.8 (1.1)	
		At mean follow-up of 44m	0.3 (0.6)	0.8 (1.0)	Change in symptom score ns in logistic regression controlling for age and sex. Symptom score at follow-up ns for treatment.
As above: Mannheim trial	As above	Before treatment	3.3 (1.2)	3.8 (1.7)	
		After treatment	0.3 (0.5)	0.9 (1.6)	
		At mean follow-up of 44m	1.5 (1.7)	2.0 (1.4)	Change in symptom score ns in logistic regression controlling for age and sex. Symptom score at follow-up ns for treatment

3.3.5 Impact on education and/ or social life

As with the clinical outcomes, Mattejat (2001) did not compare treatment modalities statistically but calculated effect sizes for each group from pre-treatment to post-treatment, from pre-treatment to follow-up, and from post-treatment to follow-up (see Table 12). This was followed by logistic regression to examine which factors influenced long-term outcome and whether there were any differences in outcome dependent on treatment group. The logistic regression showed no significant difference in changes in adaptation scores between treatment groups in either trial, when age and sex were controlled. By contrast, the trial carried out in Marburg showed a

significant treatment effect when scores at final follow-up were compared. This indicated better adaptation for those who had received home treatment, although the authors suggest that the 'difference is negligible considering the absolute figures and the corresponding effect sizes' (*ibid*: 77). This effect was not observed in the Mannheim trial. A comment in Table 9 of the paper suggests that girls had better adaptation scores at follow-up, but this is not reflected in the figures actually reported in the table.

Glueckauf (2002) used the Social Skills Rating System (SSRS) to assess aspects of the young person's social functioning. This measure 'assesses the frequency and importance of behaviours influencing the teen's development of social competence and adaptive functioning at school and at home' (*ibid*: 57). It covers three principal domains – social skills, problem behaviours and academic competence.

Preliminary analysis was said to show no significant difference between the outcomes of the three treatment modalities (videoconference, speakerphone, or office-based counselling). Further, no time effect or time by treatment effects were found. Because of this, the paper reports only combined results for the three treatments. Overall, the counselling intervention, regardless of how delivered, had no apparent impact on the young people's social functioning, and neither did their social functioning improve over time.

Table 12. Social outcomes for model of home care for children with mental health problems

	Clinical outcomes				
Study	**How measured**	**Period of follow-up**	**Subjects**	**Controls**	**Reported statistical significance**
Mattejat 2001: Marburg trial	Mean (SD) score: adaptation at school or work	Before treatment	3.7 (1.2)	4.1 (1.6)	
		After treatment	3.1 (0.8)	3.6 (1.4)	
		At mean follow-up of 44m	3.2 (0.6)	4.0 (1.2)	Change in score ns in logistic regression controlling for age and sex. Score at follow-up p=.0468 for treatment.
As above: Mannheim trial	As above	Before treatment	3.9 (1.3)	4.4 (1.2)	

		After treatment	2.6 (1.0)	3.3 (1.0)	
		At mean follow-up of 44m	3.2 (1.4)	3.5 (1.6)	Change in score ns in logistic regression controlling for age and sex. Score at follow-up ns

3.3.6 Impact on family or carers

The effect of the treatment on family issues was measured in the Glueckauf (2002) study with the Issue Severity Scale (ISS), the Issue Frequency Scale (IFS) and the Issue Change Scale (ICS). All three measures were developed by the lead author. Measurement was done before treatment and one week after it finished. The paper reports results only for the ISS and IFS.

As with the other outcomes reported above, results for the different groups are not reported in the paper, because preliminary MANOVA analysis had shown no statistically significant treatment or time by treatment effects. However, all groups improved over time, both in the severity and in the frequency of reported family problems, regardless of which group they were in.

Measurement of the same outcomes at six months follow-up also showed no treatment or time by treatment effects. However, again, there was a time effect.

3.4 Home care for acute physical conditions

Three RCTs of home-based care for children with acute but not life-threatening conditions were identified for the review. The first was for children with buckle fractures of the distal radius (Symons, 2001); the second for children with breathing difficulties, diarrhoea with or without vomiting, and fever (Maxwell, 2000; Sartain, 2002a and b; Sartain, 2001; Bagust, 2002; Sartain, 2000); and the third for children with acute bronchiolitis (Bajaj, 2006). The first two trials were in the UK and the third in the USA. Table 13 gives publication details for the main results paper from the three trials, referred to hereafter by the name of the first author of the main results paper. The details of the models of care and the care with which they were compared are outlined in Table 14.

In all cases, children were admitted to hospital for acute care and, after immediate treatment or a period of assessment or observation, discharged home. In the Symons (2001) trial parents were shown how to remove the child's below-elbow back slab, so that they did not have to return to the

hospital for removal three weeks after the fracture.[d] In the Bajaj (2006) trial, children were discharged with a portable home oxygen unit but with no planned care, other than a visit to the emergency department or to a primary care provider for follow-up 24 and 48 hours after discharge. In the Sartain (2002) trial, children were discharged home with the services of a nurse-led 'hospital at home' (HaH) scheme.

Table 13. Details of trials of hospital at home services

Authors and title of main paper	Publication details	N subjects	N controls	Jadad score (max 3)	EPOC score (max 7)
Symons *et al*. 2001 Hospital versus home management of children with buckle fractures of the distal radius	J. Bone Joint Surg. – Br.Vol. 83-B: 556-60	38 followed up[a.]	42 followed up	2	5
Sartain *et al*. 2002a Randomised controlled trial comparing an acute paediatric hospital at home scheme with conventional hospital care	Archives of Disease in Childhood 87: 371-75	210	189	2	6
Bajaj *et al*. 2006 A randomized trial of home oxygen therapy from the emergency department for acute bronchiolitis	Pediatrics 117: 633-40	53	39	3	5
Total randomised		*301*	*267*		

a. Numbers randomised to each group not reported. 87 children in total were randomised.

Table 14. Details of model of hospital at home care

Author and year	Country	Condition	Model of care	Compared with	Primary setting	Secondary setting
Symons 2001	UK	Buckle fracture of the distal radius	Home management of removal of backslab	Return to hospital for removal and review	Child's home	Initial treatment in hospital
Sartain 2002	UK	Breathing difficulties, diarrhoea with or without vomiting, fever.	Hospital at home. Nursing care providing planned visits until 23.00 hours and	Hospital care	Child's home	Initial assessment in hospital

[d] The back slab was applied, dried, and then cut but not removed, and then rewrapped with a bandage. Parents observed this process and were told how to remove the back slab themselves in three weeks time.

			on-call service during night. Available 7 days a week.			
Bajaj 2006	USA	Acute bronchiolitis	Hospital at home. Early discharge from hospital with oxygen equipment. Follow-up visit to primary care provider at 24 and 48 hours.	Hospital care	Child's home	Initial observation in hospital

3.4.1 Inclusion and exclusion criteria

The Symons (2001) trial excluded children who had pathological fractures, previous problems with the wrist on the side of the fracture, bicortical fractures, and those who did not understand or were unwilling to enter the study.

For the Bajaj (2006) trial, the inclusion criteria were:

- aged between two and 24 months and a minimum of 44 weeks conceptional age
- clinical diagnosis of bronchiolitis
- chest x-ray consistent with bronchiolitis
- first episode of wheezing
- room oxygen saturation levels ≤ 87 per cent on arrival
- parents have transport to return to primary care provider or ED 24 and 48 hours after discharge
- lives at an altitude ≤ 6000ft
- lives ≤ 30 minutes from an emergency medical facility
- caregivers must maintain a smoke-free environment in home and car
- caregiver must have a contact telephone number.

The exclusion criteria were:

- pre-existing cardiac pulmonary, neuromuscular or nutritional disorder
- pre-existing congenital pulmonary or acquired airway anomalies
- history of apnoea
- acute bacterial pneumonia confirmed by chest x-ray
- prior episode of wheezing.

- steroid administration.
- caregivers unable to stay with child in the observation unit.

The Sartain (2002) trial was for children (aged 0 to 15 years) with breathing difficulties, diarrhoea with or without vomiting, or fever (pyrexia). The general inclusion criterion was that they were likely to need more than 24 hours of nursing observation after assessment on the paediatric assessment ward or on the post-take ward round. The general exclusion criteria were that the child was considered 'unsuitable' by the GP, or by the assessing doctor or nurse; that parents were unwilling or unable to participate; that parents did not have telephone access; and that the child was registered with a GP outside the trial Health Authority.

Specific inclusion and exclusion criteria for each condition were:

- Pyrexi.
  - aged 6 months or over
  - not after a febrile convulsion.
- Diarrhoea (with/without vomiting)
  - aged 6 weeks or over
  - diarrhoea not excessive (>4 in 4 hours) or bloody
  - not dehydrated of without adequate urine output
  - if vomiting or refusing feed must take one clear feed (at least 10ml/kg) without vomiting for 1 hour
  - must be alert
- Breathing difficulties
  - age 6 weeks and over
  - if age less than 6 months must have had symptoms for at least three days
  - saturations in air ≥ 92% and not tired or pale
- Asthma
  - able to talk in sentences
  - no accessory muscle use
  - over age of five: best or predicted peak flow > 50%, pulse < 120 and respirations < 40
  - under age of five: pulse < 140 and respirations < 50
  - under 6 months pulse < 140 respirations < 60
  - above values must be pre-treatment or 2 hours after last treatment
  - stridor, if present, must be intermittent.

Symons (2001) reported that 154 children had been diagnosed with buckle fractures of the distal radius in the eight months of the trial, 101 of whom were referred to the study team. Eleven met an exclusion criterion and two wanted to be followed up in another city.

Neither Sartain (2002) nor Bajaj (2006) gave any information about the size of the paediatric hospital population from which the trial participants were drawn. However, in the economic evaluation paper associated with the

Sartain (2002) trial (Bagust *et al*., 2002) it was suggested that eligible patients constituted around 10 per cent of total paediatric work load (*ibid*: 491).

Sartain (2002) reports that 464 eligible children were identified, over what seemed to be a 14 month period (17 months of data collection, minus the 90 day follow-up period). This was in a hospital with a 64-bedded paediatric unit serving a population of 84,000 children. Bajaj (2006) gives no comparable information, although the paper does report that the sample was generated over three consecutive 'winter seasons' between December 1998 and April 2001.

3.4.2 Quality of the trials

As shown in Table 13, these were among the better quality trials identified in the review. Symons (2001) scored 2 on the Jadad criteria and 4 on the EPOC criteria. Bajaj (2006) scored the maximum on the Jadad criteria, but did rather less well on the EPOC criteria. By contrast, Sartain (2002) did less well on the Jadad criteria (because of limited description of randomisation processes and no description of those who dropped out of the study) but much better on the EPOC criteria. Across the three trials, 301 children were randomised and/or followed up (see table) to a home care option and 267 to usual hospital care.

3.4.3 Outcomes reported

The aim of the Symons (2001) trial was to demonstrate clinical safety and satisfactory care. No primary outcomes were specified but a range of clinical outcomes was assessed six weeks after the initial fracture.

The primary outcome of the Sartain (2002) trial was reduction in readmissions, with power calculations based on evidence about readmission rates for children with similar conditions in a previous year. Secondary outcomes were A&E attendances within 90 days, length of stay, and (from qualitative interviews with a sub-sample) the children's and parents' satisfaction with the quality of care received. Data on health service costs and costs to the families were also collected and reported.

Primary outcomes in the Bajaj (2006) trial were failure to meet discharge criteria during the observation period, return to hospital after successful discharge, and incidence of serious complications. Power calculations were carried out in relation to the last two of these outcomes but it is not clear whether real data were used to estimate the hoped-for effect size. Secondary outcomes were caregiver satisfaction, caregiver preference, and the primary care providers' satisfaction and preference. No costing data were collected for the health service but days of work lost by caregivers were reported.

3.4.4 Length of hospital stay and readmission

Sartain (2002) reports total days of hospital or HaH care (see Table 15). This shows that children in the HaH group had significantly more days of care (including readmissions, Haycox, 2008, personal communication) than did those in the hospital group.

Initial days of care in the Bajaj (2006) trial were not reported for both groups, but as the home care group all left hospital after eight hours of observation it seems reasonable to assume that the average length of initial episode was one day. However, average days of home care with oxygen were not reported either, so a direct comparison of bed/care days for the two groups was not possible. One child was readmitted from the home care group and spent 45 hours (2 days) in hospital as a result. It is not reported whether any of the hospital care group returned to hospital after discharge during the same period, although 26 of the 33 children in this group were also discharged on home oxygen.

Table 15. Length of total bed/ care days in hospital at home trials

	Days of total bed/ care days Mean or median* (range)		Reported significance	Shorter or longer stays for subjects
Study	Subjects	Controls		
Sartain 2002	2 (0-9) * (mean 2.37)	1 (0.10)* (mean 1.37)	p<.0001	Longer
Bajaj 2006	Not reported directly	1.83 (0.58 – 6.33)	n/a	n/a

3.4.5 Clinical outcomes

Symons (2001) reported a range of clinical outcomes for the 80/87 children who were followed-up at six-weeks. These were swelling, tenderness, deformity, wrist movement, effect on writing and activities of daily living, and management of hobbies. In no case was there any significant difference between those seen at the hospital at three weeks and those who were not.

There was no reporting of clinical measures in the other trials but both reported adverse events, complications or readmissions. These data are summarised in Table 16.

The Sartain (2002) trial reported a higher, but statistically non-significant, number of readmissions among the HaH group than in the hospital care group. Further, there was a tendency for children who had been cared for in the HaH scheme to be readmitted for the same condition for which they had originally been admitted. This was apparently related predominantly to children with breathing difficulties. Again, however, this difference did not reach statistical significance.

Table 16. Adverse events, complications or readmissions in hospital at home trials

Study	Measure used	Period of follow up	Subjects	Controls	Reported statistical significance
Sartain 2002	Number of readmission episodes	90 days	21 (10%)	15 (7.8%)	p=.49
	Children with no readmissions	90 days	193 (92%)	175 (93%)	p=.85
	Length of time from discharge to first readmission		Up to 1 week 2 (12%) Over 1 week 15 (88%)	Up to 1 week 5 (36%) Over 1 week 9 (64%)	p=.20
	Diagnosis on readmission		Same diagnosis 15 (71%) Different diagnosis 6 (29%)	Same diagnosis 6 (40%) Different diagnosis 9 (60%)	p=.09
	Presenting problem group of readmission		Fever 2 (10%) Diarrhoea 1 (5%) Breathing difficulties 18 (86%)	Fever 5 (33%) Diarrhoea 2 (13%) Breathing difficulties 8 (53%)	p=.10 (p=.06 breathing difficulties vs others)
Barjaj 2006	Complications after randomisation and withdrawn from study	8 hours for home care group, end of hospital stay for hospital group	2 diagnosed with pneumonia[a.] 2 poor oral intake[b.] 2 worsening respiratory status[c] 1 change in diagnosis to reactive airways disease[c.]	2 diagnosed with pneumonia$_3$	Not tested
	Readmission		1 (27%) 95% CI 0.6 – 13.8	0	

a. Should have had x-ray before randomisation and excluded at that stage – withdrawn from study

b. Completed observation period but 'failed' and admitted to hospital for further care

c. Withdrawn from study

The Bajaj (2006) results on complications and readmissions are difficult to interpret because of the way the trial was designed. First, there were two children in the home care group who were randomised before their chest x-

rays were seen, and who were then diagnosed as having pneumonia. These children were thus never eligible for randomisation and were excluded from the study. Similarly, two children in the hospital care group diagnosed with pneumonia were withdrawn from the study, although it is not clear at what point this was done. However, five other children randomised to home care, 'failed' the observation period, because they had poor oral intake, because their respiratory function deteriorated or because they were diagnosed with a problem other than bronchiolitis.

It was methodologically correct to withdraw the child with a different condition from the trial. However, children who developed complications after randomisation should perhaps have been retained for purposes of analysis. This is because the observation period came after randomisation and while both groups were observed for eight hours, this was done in the ED observation unit for the home care group and in the hospital proper for those admitted to hospital care. Further, those admitted to hospital could receive other forms of treatment from their attending physician. It seems reasonable to argue, then, that the children who developed complications during the observation period should have been retained in the study in an intention to treat analysis.

Other children were withdrawn from the study because of parental anxiety (2 home care, 1 hospital), resolution of the need for oxygen during observation or before admission (5 home care, 1 hospital), transfer to another facility (1 home care), and incomplete data (2 hospital). If we include all those randomised, seven of the 53 children randomised to home care (13%) and two of the 39 children randomised to hospital care (5%) experienced some form of complication. This difference does not reach statistical significance, and is offset, perhaps, by the higher proportion of children in the home care group whose need for oxygen resolved during the observation period. However, the home care group had a significantly lower requirement for oxygen during the observation period (mean L/min 0.436 compared with 0.560 for the hospital care group, Student's t test, p=0.037) so the higher proportion of spontaneous resolution may not be unexpected.

3.4.6 Health care costs

Symons (2001) and Bajaj (2006) did not report any health care costs.

The Sartain (2002) trial included an economic evaluation (Bagust *et al.*, 2002). This covered both the privately borne (parental) costs of HaH compared with conventional in-patient care and the NHS costs.

The main data sources used for the NHS element of the work were inpatient days per index admission, subsequent readmission for related conditions within 90 days, days of HaH care provided, and the number and duration of home visits made and the distance travelled per visit. The costing was both top-down (for inpatient care and based on CIPFA data for 1999-2000) and bottom-up (for staff and non-staff costs of home visits and travel costs). The overall conclusion of the analysis presented is that NHS costs per

patient appear £130 greater for HaH than for hospital care (£870 and £741 respectively).

However, these figures are dependent on service capacity and over-capacity. As is often the case when evaluating new service models (see, for example Wilson et al 1999) slow initial take up means that the number of patients cared for was 'substantially below that envisaged in normal clinical practice' (Bagust *et al*., 2002: 491). The HaH team leader estimated that the service could comfortably manage 50 per cent more cases than seen during the trial. Had this been the case, the staffing costs of the service would have fallen from £707 per patient to £470. Further, the longer-term implications of HaH services depend crucially on 'how efficiently the new service is operationalised alongside a traditional paediatric hospital service (for example, rationalisation of bed capacity)' (*ibid*).

Because of these caveats, the economic evaluation concludes that it is not possible to draw firm conclusions about the relative costs of HaH compared to conventional hospital care because this 'will depend on the manner in which it is introduced and managed, and even on local accounting practice' (Bagust *et al*., 2002: 492).

3.4.7 Family costs

Symons (2001) did not report any family costs but the other two trials reported some aspect of financial impact on families.

Sartain (2002) collected both direct and indirect family costs from 75 per cent (300) of the families in their study, reported in the separate economic evaluation (Bagust *et al*., 2002). Data on journeys to hospital and their cost, food expenditure, telephone calls, childcare costs, and 'other' costs associated with the period of care were collected. Total direct costs for families when their child had received the HaH service were significantly lower than for those whose child had been in hospital (Table 17). As might be expected, mean total travel costs and childcare costs were significantly lower for those whose child had received HaH care, and these items contributed the most to the significant difference between the two groups.

Only 121 families (30% of the total) provided data on whether any family member lost days of paid work because of the child's illness. There was no difference between the groups in reported absence rates (76% HaH, 75% hospital care, p=.84) or mean number of days lost per family (see Table 17). However, early randomisation for the HaH families was associated with a lower rate of absence (43% compared to 90%, p<.001) and slightly less total time away from work (0.98 compared to 2.32 days, p=.09). This pattern was not observed among families whose child was cared for in hospital. The researchers comment that, where possible, admission to HaH should be rapid as delay, 'increases the likelihood of parents losing working time' (Bagust *et al*., 2002: 491).

Bajaj (2006) did not collect data on direct costs but did explore the number of days of paid work lost by families. There was no significant difference

between the groups but the finding did favour the group whose children were cared for at home (see Table 17).

Table 17. Family costs reported in hospital at home trials

Study	Measure used	Period of follow up	Subjects	Controls	Reported statistical significance
Sartain 2002	Total mean direct costs incurred by families[a.]	During period of admission	£13.76	£23.31	p=.001
	Mean days missed from paid work[b.]	During period of admission	2.4	2.5	p=.85
Bajaj 2006	Mean days missed from paid work	During period of care	1.72	2.69	p=.145

a. Data from 300/399 families.

b. Data from 121/399 families.

3.4.8 Satisfaction with services

Symons (2001) used a 'visual analogue scale' to measure parent and patient satisfaction with the treatment of the children's fracture, but this measure was not further described. The results were not reported directly but were said to show that both groups were highly satisfied with the care received. Five parents in the home group and 14 in the hospital group reported experiencing problems with care of the child's fracture. All those in the hospital group reporting problems elaborated on these. They included complaints about hospital waiting times (10), difficulty getting time off work to attend hospital appointments (5), transport difficulties (3), and inadequate hospital car parking (2). Another had removed the uncut back slab at home in order to avoid losing time at work. Only two of the home care parents chose to elaborate on their problems; in one case, this related to wanting a spare bandage for the back slab and in the other that the child had removed the back slab before the given date.

Parents were asked if they would choose to repeat the form of treatment received if, in the future, they were given a choice between hospital or home removal of the back slab. The difference in responses between the two groups was said to be highly significant (p<.001) with those in the home group much more likely to prefer the same treatment again, compared with those in the hospital group.

The Sartain trial included a sub-study of 40 families (20 in each group) who were interviewed about their experiences of hospital care and HaH (Sartain *et al.*, 2001). There were very few differences between the groups in their expressed satisfaction with their child's care, although those who had experienced HaH were somewhat more likely to say that they were very

satisfied with care than were those whose children were in hospital (70% and 55% respectively). Families whose child had been in hospital were slightly more likely to report that this form of care had had a negative effect on the child (10% vs. 0%) while those whose child had received HaH services were more likely to report that this type of care had had a positive effect (80% vs. 5%). However, the numbers involved were too small for this difference to reach statistical significance (p=.1468). Parents of children cared for at home were slightly more likely to report being well informed about their child's illness and care (80% vs. 60%, p=.1675) and to feel that nursing staff were supportive and reassuring (80% vs. 65%, p=.7111). Overall, 90 percent of both groups said that, given a choice, they would choose HaH care rather than hospital care.

The views of 11 children, ranging in age from five to 12 years, were also surveyed, via semi-structured interviews and drawings. Children who had been in hospital were reported as having 'the most to say' about their experience and, on the whole, were not negative about the experience; indeed two had enjoyed it so much that they would choose to go to hospital if they had a similar illness again. However, three said they would choose home care 'next time' and one was unsure. Four of the children who received HaH services said they would choose the same again, one was unsure and none would choose hospital (figures derived from Table 4 and text, Sartain *et al*., 2001).

Bajaj (2006) also reported aspects of 'caregiver' satisfaction, but only for the children who had received home care. Follow-up was not complete – 33/37 caregivers were contacted at 24-hour or 48 hour, at 33/37 at 72-hour follow-up, and 35/37 at the seven-day follow-up. At the 24-hour or 48-hour follow-up of the child, 32 caregivers reported being 'satisfied with their child at home'. At the 72-hour follow-up, caregivers were asked about their preferences about place of care. Twenty-six reported that they preferred to have their child at home, five that they would have preferred to have the child in hospital and two had no opinion. There were also asked whether they felt that the observation period in the hospital had been the right length. One caregiver felt that it had been too short, 13 the right length, 15 too long, and the remaining four had no opinion. All the home care families reported that they had received adequate instruction on use of the home oxygen.

At the seven-day follow-up, 33 said that they were satisfied with home oxygen for their child.

3.4.9 Impact on family and/ or carers

Symons (2001) did not report any aspect of impact on family or carers other than those related to satisfaction (see above). Similarly, Bajaj (2006) did not explore any aspect of impact on families other than days missed from work (see above).

The Sartain (2002) trial took two approaches to exploring impact on families.

First, a diary card was used to collect details of the time parents or carers spent in various social and physical childcare tasks. Only 125 families completed this – 69 whose child was in hospital and 56 whose child used HaH services. This difference in completion rates was not statistically significant, but it is not clear whether the groups who did return the data were otherwise similar.

Overall, families of those who were in hospital spent a mean of 169 minutes on physical care activities (changing nappies, feeding, bathing, taking temperatures, medication, and putting to bed) compared to a mean of 215 minutes for families of children cared for at home. This difference did not reach conventional levels of statistical significance (p=.08). The mean physical care time per patient per day was 137 and 117 minutes respectively (p=.28). Similarly, for social care activities (playing, cuddling, talking/singing, and calming/comforting) the time spent was somewhat, but not significantly, lower for children cared for in hospital compared to those cared for at home (185 and 195 total minutes respectively; 161 and 124 minutes per patient per day respectively).

There were some differences between the groups in specific activities. Families whose child was in hospital spent significantly less time in total than those whose child was at home in changing nappies (26 and 42 minutes respectively, p=.04) and administering medication (5 minutes and 14 minutes respectively, p=.02). By contrast, families whose child was at home spent somewhat less time overall (52 and 85 minutes respectively, p=.09) and significantly less time per patient per day (26 and 74 minutes respectively, p=.004) in play activities.

Secondly, Sartain (2002) included a sub-study of 40 families, interviewed using a semi-structured schedule (Sartain *et al*., 2001). The families were equally divided between those whose child had been in hospital care and those whose child had received HaH care, but were not sampled randomly from the two groups. Only some of the questions asked of parents related to the impact on the family. For example, 16/20 of parents whose child was in hospital and all of those whose child received HaH care reported that their involvement was high. However, only one parent in each group reported that their responsibilities were 'too high'. Hospital at home appeared to reduce the disruption to family life that the child's illness caused: 11/20 of those with a child in hospital and only 1/20 of those using HaH care reported that the child's illness disrupted family life 'greatly'. This difference between the two groups was reported as statistically significant (p=0.0006). Further, rather more of the HaH group parents reported that they had learned new skills from nursing staff (5/20 compared to 3/20 in the hospital group). Given that the two sub-groups were not randomly selected, it is difficult to know how much weight to give to this finding; however, it makes intuitive sense.

Analysis of the more qualitative material gathered in the sub-study showed that most parents whose children had been in hospital would have preferred HaH services. They felt that HaH would have involved less overall disruption and fewer alterations to routines such as paid work and child-care

arrangements. Most of those who had experienced HaH also felt it was preferable to hospital admission. Again, issues about disruptions to family life were predominant.

3.5 Home chemotherapy

One, small, randomised cross-over trial of home chemotherapy for children with high-risk acute lymphoblastic leukaemia in Canada was identified (Stevens, 2006). The model of care involved the child receiving initial chemotherapy in hospital and the remainder at home. This was compared with all chemotherapy being received in hospital.

3.5.1 Inclusion and exclusion criteria

The trial was for children aged two to 16 years of age diagnosed with acute lymphoblastic leukaemia (ALL) in the year prior to enrolment in the study. They had to be receiving treatment for high-risk ALL from a paediatric oncologist, based on a standard protocol, being cared for at home by parents, and living in a greater metropolitan area of central Canada. Other inclusion criteria included the ability to speak and read English or having an interpreter available (presumably this applied to both the children and the parents, although this is not clear). Exclusion criteria included other major congenital illnesses and those without patent central venous catheters for the administration of medication. Although not mentioned as a formal inclusion criterion in the methods section of the paper, the abstract states that the children were attending the outpatient clinic of a tertiary paediatric hospital *and* were receiving home care visits from a community health services provider.

There was no indication of the total population of children with ALL being treated at the hospital, but 50 were reported to have met eligibility criteria during the (unspecified) period of recruitment.

3.5.2 Quality of the trial

This was a high quality trial as assessed by the Jadad criteria but did less well on the EPOC criteria (see Table 18), because it was not clear that allocation was concealed or that the primary outcomes were assessed blindly. Final follow-up was also somewhat below 80 per cent.

Table 18. Details of trial of home chemotherapy

Authors and title of paper	Publication details	N subjects	N controls	Jadad score (max 3)	EPOC score (max 7)
Stevens *et al.* 2006	Pediatric Blood Cancer, 47: 285-292	15	14	3	4

3.5.3 Outcomes reported

The primary outcome was defined as the child's quality of life and secondary outcomes included effects on parental caregivers, adverse clinical effects and costs. Outcome data were collected at up to five points during 12 months of follow-up.

3.5.4 Adverse clinical events

The analysis presented for this outcome was mostly descriptive. There were no significant differences in the problems reported with chemotherapy administration or port access between the groups across time and no significant differences in problems requiring a call to the community nurse or oncologist. However, reports of other adverse events were statistically different for follow-up at times three and four. Here, four children in the home care group and four in the hospital group who did not report events at time three reported events at time four. The authors argue that, because of the cross-over nature of the trial, which meant that the location of treatment changed across these time points, these events could be associated with a change in routine.

3.5.5 Family costs

Data on families' use of health services and the costs of care to them were collected using the Health Service Utilization and Costs of Care Inventory. This included both direct and indirect costs, such as visits to physicians, expenditure on medications and supplies, baby sitting and travel as well as lost income or productivity. Data were collected on five occasions over 12 months. The average costs for the families of children receiving home chemotherapy were Canadian $851 and for those receiving hospital chemotherapy $1050.This difference was not statistically significant (S = 8.5 p = 0.79)

3.5.6 Quality of Life

The child's quality of life was assessed using the Paediatric Oncology Quality of Life Scale at five points during the 12-month follow-up period. Results were presented descriptively.

Children in the home chemotherapy group were said to have experienced a decrease in QoL in relation to sensitivity to restrictions in physical functioning and maintaining a normal routine when they crossed over to the hospital-based treatment (average change of +5.2, with increased score indicating decreased QoL). By contrast, the children who switched from hospital to home care experienced an improvement in their QoL scores (average change -10.5). The difference between the two groups was statistically significant (Wilcoxon statistic=80 p=0.023). Change in emotional distress and reaction to current treatment did not differ significantly for the two groups. Paired comparisons at the end of each 6

month period showed lowered QoL in relation to emotional distress in the home care group compared to hospital group (Wilcoxon S=66 p=0.043).

3.5.7 Impact on family and/ or carers

Parental burden of care was reported not to differ between hospital or home-based care.

3.6 Home-based alternatives to clinic-based care

Two trials of care that could be delivered at home instead of in an outpatient, clinical setting were included in the review. The first (Griffiths, 1996) was a trial of clinic-based versus home-based treatment for children with chronic headaches. The second (Braga, 2005) compared clinic-based versus home-based rehabilitation for children with traumatic brain injury (TBI). Table 19 gives publication details and quality scores for the papers reporting the trial results. The first trial was in Australia and the second in Brazil. The details of the models of care are outlined in Table 20.

Table 19. Details of trials of home-based versus clinic-based care

Authors and title of paper	Publication details	N subjects	N controls	Jadad score (max 3)	EPOC score (max 7)
Griffiths and Martin 1996 Clinical - versus home-based treatment formats for children with chronic headache	British Journal of Health Psychology, 1: 151-166	15	15 clinic 12 waiting list control	1	1
Braga *et al*. 2005 Direct clinician-delivered versus indirect family-supported rehabilitation of children with traumatic brain injury: a randomized controlled trial	Brain Injury, 19: 819-831	44	43	2	5

Table 20. Details of model of home-based versus clinic-based care

Author and year	Country	Condition	Model of care	Compared with	Primary setting	Secondary setting
Griffiths 1996	Australia	Chronic headache	CBT programme delivered at home with minimal therapist involvement	CBT programme delivered in clinic-based group format	Home	Clinic

Braga 2005	Brazil	Traumatic brain injury	Rehabilitation programme delivered at home by parents, plus case manager support	Rehabilitation programme delivered in a clinic setting by professionals	Home	Clinic visits for follow-up and adjustment of programme

3.6.1 Inclusion and exclusion criteria

Children in the Griffiths (1996) trial were aged between 10 and 12 and had a medical diagnosis of migraine, tension headache or both, and chronic headache, defined as at least one headache a week for the past six months. They had to be able to attend up to eight clinic-based treatment sessions accompanied by one parent. Children receiving current psychological treatment for headaches were excluded.

Inclusion criteria for the Braga, 2005 trial were as follows:

- Children aged between five and 12 years old
- History of moderate or severe TBI. Moderate was defined as a Glasgow Coma Scale score of nine to 12 or greater than 12 if accompanied by diffuse brain swelling, skull fracture or intracranial mass. Severe was defined as a Glasgow Coma Scale score of below eight.
- TBI between six to 30 months prior to the beginning of the study
- Evidence of chronic impairment in cognitive and/or physical domains
- Family were willing to participate.

Exclusion criteria were:

- Significant vision or hearing loss
- Serious psychiatric diagnosis
- Unresponsive state
- Not attending regular or special school
- Frequent drug-resistant seizures
- Family were unwilling to participate.

In neither study was any indication given of the size of the patient population from which the study participants were sampled.

3.6.2 Quality of the trials

Reporting of methodological details of the Griffiths (1996) trial was poor with resulting low scores on both the Jadad and EPOC criteria. The Braga (2005) trial achieved relatively high scores, but was let down by reporting of details of dropouts from the trial and uncertainty about concealment of allocation (see Table 19).

3.6.3 Outcomes reported

Griffiths (1996) reported clinical and psychological function outcomes, along with some judgement of health costs. Braga (2005) reported physical function and mental function outcomes only.

3.6.4 Clinical outcomes

No direct results were reported in the Griffiths paper but it is possible to read off values from the two figures presented (see Table 21). The statistics reported in the paper do not compare the home-based group against the clinic-based group and the waiting list controls. Rather, each group was compared with itself over time, making this an efficacy rather than an effectiveness trial.

Table 21. Clinical outcomes from trials of home-based versus clinic-based care

Author and year	How measured	Period of follow-up	Subjects	Controls	Reported statistical significance
Griffiths 1996	Mean headache index score[a.]	2 weeks after treatment	9	4 (clinic) 13 (waiting list)	p<.002 (home) p<.0001 (clinic) NS (waiting list)
	Mean % (SD) change in headache index score		65.2 (31.8)	70.3 (55.1) clinic -58.8 (202.7) waiting list	Not reported
	Proportion of group showing clinically significant improvement in headache index score		62%	80% (clinic) 25% (waiting list)	p=.007[c.] (clinic vs waiting list) p=.121[c.] (home vs waiting list)
	Medication score[b.]		0.50	0.58 (clinic) 3.0 (waiting list)	NS for all three groups

a. Assessed from contemporaneous recording of severity of headache at four points during day for seven days a week. Read by us from Figure 1.

b. Number of tablets taken for headaches each week from contemporaneous recording. Read by us from Figure 2.

c. Reanalysed by us, Fisher's exact test, 2-sided.

The analysis shows that both the home-based and clinic-based groups demonstrated improvement from baseline to post-treatment follow-up on the headache index, although the improvement in the home group was less than that in the clinic-based group. By contrast, the waiting list control group showed no significant improvement over time.

The proportion of children who experienced clinically significant improvement in the headache index score (defined as achieving 50 per cent or more percentage improvement) varied between the three groups and, as might be expected, the two treatment groups did better than the waiting list control group. Analysis presented in the paper suggests no significant difference between the two treatment groups. However, reanalysis by us of the results for all three groups indicated that, while the difference between the three groups was statistically significant, the difference between the clinic-based group and the waiting list group contributed most to this. Indeed, a comparison between the home-based group and the waiting list controls showed no statistically significant difference between them.

None of the groups showed any statistically significant change over time in mean medication score.

3.6.5 Physical functioning

Braga (2005) assessed physical and motor functioning using a scale developed specifically for the service being evaluated (the SARAH scale). The scale was not validated or tested for reliability before the study reported here although this process was said to be 'currently underway' (*ibid*: 825). Within-group comparisons of change showed that the home-based group made significant progress from baseline to follow-up (p=0.011) but that the hospital-based group did not (p=.358). Between group comparisons showed a significantly different rate of progress for home-based rehabilitation (see Table 22).

Table 22. Physical function outcomes from trials of home-based versus clinic-based care

Author and year	How measured	Period of follow-up	Subjects	Controls	Reported statistical significance
Braga 2005	Mean (SD) SARAH scale score	At baseline	2.5 (1.3)	2.4 (1.3)	
		After 12m treatment	3.1 (0.8)	2.6 (1.1)	p=0.018 (between groups)

3.6.6 Psychological and mental functioning

Griffiths (1996) reported the impact of the models of care on self-efficacy, coping responses, anxiety and depression. Again, however, the statistical analysis presented explored change over time within the three groups but not differences between the groups. This showed that none of the groups

improved on the measure of self-efficacy between baseline and follow-up but that coping responses improved significantly between baseline and follow-up for both the home-based and clinic-based groups but not the waiting list control group. Anxiety scores decreased significantly between baseline and follow-up for the clinic group but not for the home-based or waiting list control group. There was no significant change for any group between baseline and follow-up on the depression measure.

In Table 23 we present the mean change between baseline and follow-up for the three groups in the Griffiths 1996 study. This suggests that the home-based group did little better than the waiting list control group on the anxiety and depression measures. By contrast, the clinic group appeared to make gains in terms of anxiety although they, like the waiting list control group, had higher mean anxiety scores (14.5, SD 6.3) and 15.6 (SD 9.0) respectively) at the outset than did the home-based group (11.7, SD 4.9).

Table 23. Psychological or mental function outcomes in trials of home-based versus clinic-based care

Author and year	How measured	Period of follow-up	Subjects	Controls	Reported statistical significance
Griffiths 1996	Change[a.] in mean Self-efficacy questionnaire[b.] scores	2 weeks after treatment	1.7	0.9 (clinic) -0.3 (waiting list)	Not reported
	Mean (SD) coping responses[c.]		0.9	1.0 (clinic) - 0.1 (waiting list)	Not reported
	Mean (SD) anxiety score[d.]		- 1.8	- 5.2 (clinic) - 2.0 (waiting list)	Not reported
	Mean (SD) depression score[e.]		-0.3	-0.5 (clinic) -0.2	Not reported
Braga 2005	Mean (SD) WISC III score	After 12m treatment	91.4 (15.6)	85.3 (15.2)	p=0.05

a. Calculated by us.

b. Unpublished questionnaire developed at Ohio University.

c. From section of Children's Headache Assessment Scale (Budd and Kedesdy, 1989).

d. Revised Child's Manifest Anxiety Scale (Reynolds and Richmond, 1978).

e. Children's Depression Scale (Land and Tischer, 1983).

There was little apparent difference between the clinic and home-based groups on the coping measure, but the home-based group did seem to do rather better on the self-efficacy measure. However, given that this was an apparently un-validated measure it is difficult to know how much confidence to ascribe to this difference.

Braga (2005) reported change on IQ scores, as measured by the Weschler Intelligence Scale for Children (WISC). The results suggest modest but statistically significant greater levels of improvement in the children with TBI in the home-based group compared to the clinic-based group.

3.6.7 Health care costs

Griffiths (1996) did not carry out any formal assessment of health care costs but did report the mean number of hours of therapist time (including clinic session time and telephone calls to participants in the home-based group) per participant in the clinic-based and the home-based groups (12.00 and 4.75 respectively). These data were used to assess what the authors term 'cost effectiveness' by 'dividing the mean percentage change [in headache index score] by the total amount of therapist time per subject for each group.' (Griffiths, 1996: 154). The data for this calculation are not reported separately, but the paper states that 'for every hour of therapist time, the home-based group achieved a mean reduction of 14 per cent in their headache index scores compared to 6 per cent for clinic-based group' (ibid). The difference between the two groups is said to be highly significant in favour of the home-based group ($t(28) = 3.67$, $p<.01$).

3.7 Telemedicine

One RCT of telemedicine was identified, published in a single paper (Morgan, 2005). This reported the early stages of a trial of regular videoconferencing links and open access to videoconferencing for emergency videoconferences to support the families of children discharged from hospital with complex congenital heart disease. The paper refers to results from the trial still being analysed. Contact with the author confirmed that results had been published subsequently (Morgan *et al*., 2008).

The study was carried out in Northern Ireland. Morgan (2005) says that the study compares the home videoconferencing service with two control services - regular telephone contact using the same protocol as for the videoconferencing group, and the *ad hoc* telephone support that was available routinely. However, the later paper (Morgan *et al*., 2008) refers only to one control group – those using the regular telephone contact using the protocol.

3.7.1 Inclusion and exclusion criteria

Patients were selected for the study if they had a severe and acutely life-threatening cardiac diagnosis and would require 'significant support' when they were discharged from hospital. No other details about the inclusion or exclusion criteria or the nature of the sample recruited were given. Fourteen families were randomised to the videoconferencing arm of the trial, nine to the 'usual care' arm, and 13 to the regular telephone calls group. The purpose of the latter group was to provide a placebo comparison.

Children under the age of three with a new diagnosis of significant CHD, that was acutely life-threatening or likely to require surgery within a year, and those admitted for palliation of surgical correction of a known significant defect were eligible for inclusion. No exclusion criteria are reported.

There is no indication of the numbers of children in the total population but 16 were randomised to the video group and 14 to the telephone group, although two of the former and one of the latter later withdrew.

3.7.2 Quality of the trial

The trial is reported as randomised but limited information about its methods or design are reported in either paper. As a result, it scores only one point on the Jadad criteria and one on the EPOC criteria.

3.7.3 Outcomes reported

Morgan (2005) suggested that the trial collected data on families' quality of life and their use of other health services but none of these are reported formally in the paper. Most of the paper is taken up with the technological aspects of delivering the videoconferencing links.

Morgan et al (2008) states that the primary end point for the study was anxiety in 'families', measured using Spielberger's state-trait anxiety inventory. Parents' views about the videoconferencing and telephone support were also collected, as were clinical data about the child when the parents were in contact. The latter were not reported.

3.7.4 Satisfaction with services

Morgan *et al.* (2008) reports that parents 'found videoconferencing statistically significantly more beneficial than telephone calls by 26.9% (95% confidence interval: 12.9 to 40.9%)' (p.320). It is not clear whether this is based on a comparison of the two groups or the video group's relative assessment of two methods of receiving support. It is also claimed that summed Likert scores of parents' opinions about videoconferencing favoured this method. Again, it is not clear what is being compared here.

3.7.5 Impact on family and/ or carers

Morgan *et al*. (2008) claims that there was no difference in baseline trait anxiety levels between the two groups of 'participants' (it is not clear whether these were mothers or fathers of the child). However, it was state anxiety that was measured in the study, as this assesses how people feel 'right now' rather than 'in general'. Anxiety was measured before and after contact with the hospital at each videoconference or telephone call and change calculated by subtraction. Data are not reported directly but by use of a box and whisker plot. The paper suggests that there was a statistically significant decrease in anxiety levels in both groups, but that the video

group experienced a statistically significant greater reduction than the telephone groups. No statistical results are reported directly, only p values.

3.8 Discussion and conclusions

On the basis of the material reviewed in this chapter, there is little to be added to the overall conclusion of the earlier systematic review of paediatric home care (Parker *et al*., 2002).

One additional trial of supported early discharge for low birth weight or medically fragile babies suggests that overall days of care are lower for those discharged early, with the early discharged group gaining weight more rapidly than those who remained in hospital longer. With equivalent costs for both groups, this does suggest a degree of cost effectiveness associated with this model of care. The studies reviewed in the earlier studies showed no differences in clinical outcomes but apparently reduced costs. There was no assessment of impact on or the costs of care for family members in the new study, as was the case with studies in the earlier review.

One new trial of a model of care for children with diabetes was included, although as noted earlier it was not clear if this included home care. This reported equivalent outcomes for children treated for newly diagnosed diabetes in hospital or in outpatient settings. It is unfortunate that, despite repeated attempts, we have been unable to obtain more detailed results for this trial, which is reported only as a conference abstract.

Two new studies of home care for children and young people with mental health problems were included. These suggest equivalent clinical and social outcomes for children and young people for home and in-patient care and similar levels of impact on family or carers. However, as neither trial addressed the costs of the different models of care it is impossible to say anything about cost-effectiveness. Neither did the new trials explore either the children's or their families' satisfaction with care.

The previous review did not cover home care for acute physical conditions that were likely to resolve. Since the publication of Parker *et al.* (2002), Ogilvie (2005) has published a review of hospital-based alternatives to acute paediatric admission; as it name suggests this did not include home-based alternatives but focussed on assessment units in Emergency Departments or on paediatric wards, where triage was the main intention. By contrast, our focus in the systematic review was on home-based alternatives either to ongoing hospital care or to a return to hospital for treatment after a period of home care.

In the two trials where children were discharged home rather than admitted to hospital, there was a suggestion of overall higher levels of days of care, which included readmissions. Other clinical outcomes were largely equivalent between those cared for in hospital and those cared for elsewhere, although one trial did suggest a higher level of complications for the home-care children.

Two of the studies examined family costs and both suggested a reduction in these for families whose child was cared for at home. Reduced travel costs, child care costs (for other children in the family) and less parental time away from work were associated with home care. All three trials explored some aspect of satisfaction with services and all found that parents and families were predominantly happy with home care and likely to choose it as an option if the need arose again. One trial also reported that parents whose children had been treated in hospital were likely to express a preference for home care for the future. This preference was possibly related to the reduced disruption to family life reported with home care.

Only one trial reported health costs; here home care costs were higher overall than hospital costs, but the home care scheme had not run at full capacity during the time the trial was underway. As a result, the health economists involved with the study suggest that it is not possible to come to firm conclusions about the relative costs of the two models of care.

The earlier review did not contain an RCT of home chemotherapy although other comparative studies of this model of care were included. A small cross-over trial was identified for the current review. This showed somewhat improved quality of life for children treated at home and reduced costs for families.

We also included in this review for the first time models of care where interventions were provided in children's home rather than in clinic settings. The two studies were both related to neurological conditions but at different ends of the severity spectrum – treatment for chronic headaches in one case and rehabilitation for traumatic brain injury in the other.

The study of treatment for chronic headaches showed a mixed pattern of difference and no difference in change over time on clinical and psychological outcomes for the two treatment groups. Despite this, the authors claim that home-based treatment was 'cost-effective'; they based this conclusion on their calculation of mean percentage change in score on the main clinical outcome (headache index score) per hour of therapist time in the two treatment groups.

By contrast, the study of rehabilitation for traumatic brain injury suggested improved clinical and mental functioning outcomes for children treated at home. However, with no costs reported for the two models of care it is impossible to judge whether the home-based care was cost effective.

Finally, a single RCT of telemedicine to support the families of children discharged from hospital with complex congenital heart disease was included in the review. This trial was small, did not score well on our quality criteria, and some of its reported results were difficult to interpret.

4 Other comparative studies of paediatric care closer to home

The previous review included studies that used comparative designs other than RCTs. This approach was repeated for the current review. Twenty-six studies, reported in 34 publications and evaluating 24 separate models of care were selected for inclusion and full bibliographical details are in Appendix 3.

While there was considerable variety in the interventions evaluated in these studies, several clusters were identified. The previous review identified four separate clusters relating to a type of intervention or model of care:

- Models of care that facilitated the early discharge of very low birth weight infants or those who had been in neo-natal intensive care units (NICUs).
- Ways of avoiding hospital admission or reducing the length of admission for children diagnosed with insulin dependent diabetes mellitus (IDDM).
- 'Technological' care at home.
- Home care for children with mental health problems.

In the present review, studies were identified that fitted with all but one of these original clusters; no non-RCT comparative studies were identified that studied a model of care for very low birth weight babies. There were studies that involved low-birth weight babies but these were about single interventions (for example, gavage (tube) feeding or home oxygen therapy) and were therefore included as technological care at home. As well as the three clusters above updated in this review, six new clusters were also identified. These were:

- Models of palliative care closer to home.
- Models of telemedicine.
- Models of admission avoidance in the home.
- Models of admission avoidance in hospital settings.
- Models of early discharge to the home.

In part, these new groupings reflect the slightly wider remit of the current review (see Chapter 1). They also reflect in part the development of new models of care close to home (CCTH). For example, telemedicine was in its infancy when the original review was completed and had not been formally evaluated in relation to its use with children and young people.

A range of outcomes was reported across the studies. As in the previous review, three major outcome domains are detailed here:

- clinical (including mortality)
- health service use and associated costs

- quality of life (including satisfaction with services, impact on family and child, impact on mental and physical functioning and impact on child's education).

These outcomes are reported for each of the models of care when they have been reported in the study.

4.1 Comparative approaches

As detailed in Chapter 2, studies were included in this chapter if they were not RCTs but did report comparative evidence. In some cases, a before and after approach was taken, comparing follow up to baseline; in other cases, control groups (one or more) were used. In many cases, retrospective comparisons were performed using historical patient data, and in some cases, a current intervention sample was compared with historical patient data. The comparisons made in each study are detailed for each model analysed below.

4.2 Quality of the studies

As discussed in Chapter 2, limited number of RCTs of models of care closer to home for children and young people led us to adopt a best evidence approach to the review. The evidence presented in this chapter does not have the credibility associated with evidence from RCTs due to the less rigorous designs and methods employed. Indeed, few of the studies included in this chapter can be considered robust. We discuss this in our concluding chapter, taking into account the range of factors that may have affected the validity of the findings reported in the included papers.

4.3 Note on terminology

There is considerable variation in the terms used internationally to describe care close to home and other aspects of health services for children and young people. For ease of reporting, and given the UK policy focus of the overall project, we have converted terms into their nearest 'English' equivalent; for example, 'accident and emergency department' rather than the USA usage 'emergency department'. In the section on models of *admission avoidance in hospital settings*, authors had used a variety of terms to refer to what have become known in the UK as ambulatory units. These terms included short stay wards/facilities, observation units, and assessment units.

As in Chapter 3, we also refer to studies throughout the chapter by the first author and date only with full bibliographical listing in Appendix 3.

4.4 Home care for children with Type 1 diabetes

Three studies were included here, all of which studied the impact of a paediatric diabetes home care team at the Birmingham Children's Hospital in the UK (Kirk, 2003, 2006; McEvilly, 2005). This service was established

in 1981, and at the end of 1994, an additional 24-hour diabetes nurse specialist was appointed that allowed the service to be extended from its large, tertiary base to a district general hospital (DGH) setting. Kirk (2003) examines the impact of extending the team to the new setting, while Kirk (2006) and McEvilly (2005) examine aspects of the overall impact of the model of care from its initial establishment. All three papers also refer to results from an earlier description of the home care service (Rayner, 1984), carried out soon after its establishment. Across the three studies reviewed here, retrospective audit was used to compare outcomes before and after the introduction of the home care team and its extension. Table 24 summarises these studies. Outcomes include clinical, health service use and costs to health service.

Table 24. Models of home care for children with Type 1 diabetes

Study	Country	Model of care	Condition	Sample size of intervention group	Design	Primary setting
Kirk (2006)	UK	Home care	Type 1 diabetes	Not reported	Retrospective review of patient data	Home
Kirk (2003)	UK	Home care (extending the team with a 24 hour diabetes nurse specialist)	Type 1 diabetes	Not reported	Retrospective review of patient data	Home
McEvilly (2005)	UK	Home care (incorporating new hospital site)	Type 1 diabetes	Not reported	Retrospective review of patient data	Home

Note that none of these studies examined a secondary setting.

4.4.1 Clinical outcomes

McEvilly (2005) and Kirk (2006) report the changes in mean HbA_1 level, as published in Rayner (1984). This fell from 12.8 per cent before the introduction of the home care service (in 1981) to 11.6 per cent at an unspecified point after its introduction, but reported in 1984. Kirk (2006) claims that this reduction was maintained through to 1987 (10.4%) and 1993 (10.5%). After this date, HbA_{1c} was measured, with results showing a mean value of 9.0 to 9.3 per cent (McEvilly, 2005; Kirk, 2006), which is said to 'compare[-] well with units nationally and internationally' (Kirk, 2006: 25). In 1995, at the baseline of extending the home care service to the DGH, mean HbA_{1c} level was 9.8 per cent and had fallen to 9.31 per cent by 2001 (Kirk, 2003). Both sets of results indicate, at least, a no worse level of control after the introduction and extension of the diabetes home

care service, however a test of significance was not used for either comparison. Neither is it possible to judge to what extent the apparent improvements in glycaemic control represent the impact of the home care service, secular change, or both.

Throughout the papers, it is sometimes difficult to determine whether results being reported are for the extended service alone, the original service alone, or for both services combined.

4.4.2 Health service use

Referring to Rayner's 1984 paper, both McEvilly (2005) and Kirk (2006) report that total in-patient bed days fell from 555 a year before the introduction of the diabetes home care team in 1981 to 127 a year in 1984. Kirk (2006) also reports from Rayner's paper that length of stay for newly diagnosed children fell from a mean of 12.2 days in 1980 to 4.1 days in 1984. A further fall to an average in-patient stay at diagnosis of 0.6 days is also reported, alongside an increase of children wholly home-managed at initial diagnosis from 33 per cent in 1989 to 66 per cent in 1994 (McEvilly, 2005; Kirk, 2006).

Kirk (2003), exploring the impact of extending the service to a DGH, shows a figure suggesting a change in bed days for existing patients from 58 days in 1994 to 38 days in 2001, and for new patients, from 18 bed days in 1994 to ten bed days in 2001.[e] However, the pattern is not consistent across time and, as the paper acknowledges, is influenced by relatively small numbers of children with relatively high numbers of readmissions. Further, the children in the DGH were much less likely to be wholly managed at home at initial diagnosis than were those in the tertiary hospital base. This is a particularly interesting finding, because it may be related to relative deprivation. The DGH serves a catchment area with a relatively high level of deprivation, and patients of 'Asian origin' (Kirk, 2003: 127) represented 60 per cent of those being seen at the clinic. Further, children under five years of age at presentation were eight times more likely to present with diabetic ketoacidosis if of Asian origin than were children in the same age range who were not.

4.4.3 Costs to health service

Rayner's 1984 paper had suggested that the home care service could save the NHS £26, 415 annually, based on an estimated in-patient expenditure saving of £52,917 and a cost of the service of £26,502 (as reported by McEvilly, 2005). Current savings to health services are reported by McEvilly (2005) based on assumptions about savings when a further 40 paediatric diabetes patients were incorporated into the home care service from a third hospital (Selly Oak). The average bed-days for newly diagnosed children at Selly Oak were reported as 10.4, compared with 1.7 bed days for the Birmingham Children's Hospital. Readmissions were reported as an average

[e] All figures estimated by us by reading off the published graph (Figure 1).

of 2.7 in the year before the Selly Oak patients were transferred, compared to 0.2 bed days for the home care service. On this basis, McEvilly (2005) estimates a saving per diabetic patient (at £419 per bed-day) of £1129.50 per year 'allowing for the increased nursing input' (ibid: 344).

McEvilly (2005) further makes a comparison with an Audit Commission (2000) national average figure per newly diagnosed paediatric diabetic patient of 3.0 bed days. Close examination of Figure 1 in McEvilly (2005) suggests that the average bed days per newly diagnosed patient for the Birmingham Children's Hospital in the year 2000 (to compare with the timing of the Audit Commission report) were actually 1.52 (38 bed days in total, 25 new patients, of whom eight patients were managed wholly at home). This is higher than the figure of 0.8 bed-days for the home care service given by McEvilly (2005). It is difficult to establish the associated costs reported in the McEvilly paper but these are dealt with in more detail in the health economics chapter.

4.5 Technological care at home

In the previous review, the non-RCT comparative section included studies of technological interventions such as home dialysis, home chemotherapy, central venous catheters (CVC), enteral nutrition and feeding and home nebulisers. The current review updates the evidence for the use of CVC, home intravenous therapies (IV) such as chemotherapy, and extends it for technologies such as home gavage feeding, home oxygen therapy (HOT), home traction, and home parenteral nutrition (HPN).

A total of seven studies (nine papers) were included here evaluating home gavage (tube) feeding (Sturm, 2005), HOT (two studies, McLean, 2000; Greenough, 2004), home traction (Stevens, 1995), home IV with other medical care (Raisch, 2003), home IV only (Nazer, 2006), and one study (three papers) evaluating home IV, CVC and HPN (Miano, 2003, 2003, 2004). Three studies were conducted in the USA (Sturm, 2005; Raisch, 2003; Nazer, 2006), one in Canada (Stevens, 1995) and one each in the UK (Greenough, 2004), Australia (McLean, 2000) and Italy (Miano, 2002, 2003, 2004).

Conditions targeted varied, and included cancer or cancer related complications (e.g. febrile neutropenia), chronic lung disease, pre-term babies, renal conditions, cystic fibrosis and congenital dislocated hips and Legg Perthes Disease (LPD). Designs used to evaluate these interventions also varied. There were two before and after designs (Stevens, 1995; Miano, 2002, 2003, 2004), and two making comparisons with a control group during the study period (Sturm, 2005; McClean, 2000), in the last case using multivariate analyses to isolate the discrete contribution of HOT to the experiences of parents whose pre-term babies used HOT. Three studies used patient data to make retrospective comparisons between the intervention and a control group (Greenough, 2004; Raisch, 2003; Nazer, 2006). In the case of Greenough (2004), outcomes for infants with chronic lung disease were compared between health care providers who made low

use of HOT and those who made high use of HOT. The included studies are summarised in Table 25.

Outcomes reported for studies of technological care at home included clinical outcomes (Raisch, 2003; Nazer, 2006), health service use (Raisch, 2003; Sturm, 2005, Nazer, 2006), costs to health service (Greenough, 2004, Raisch, 2003; Miano, 2002, 2003, 2004; Sturm, 2005), costs to families (Stevens, 1996), and impact on families (Stevens, 1995; McClean 2000).

Table 25. Models of technological care at home

Study	Country	Model of care	Condition	Sample size of intervention group	Design	Primary setting	Secondary setting
IV and related home care							
Nazer (2006)	USA	Home IV	Acute pulmonary exacerbations in children with cystic fibrosis	23	Retrospective review of patient data	Home	Hospital
Miano (2004, 2003, 2002)	Italy	Home IV, CVC, HPN	Cancer	158	Before/After	Home	-
Raisch (2003)	USA	Home IV, other medical care	Low-risk, chemotherapy induced, febrile neutropenia	36	Retrospective review of patient data	Home	-
Home oxygen therapy							
Greenough (2004)	UK	HOT	Chronic Lung Disease	119	Retrospective review of patient data	Home	-
McLean (2000)	Australia	HOT	Chronic Lung Disease	10	Between measures	Home	-
Other technological care at home							
Sturm (2005)	USA	Home gavage (tube) feeding	Preterm infants	52	Between measures	Home	NICU
Stevens (1996)	Canada	Home traction	Congenital dislocated hip and Legg Perthes Disease	24	Before/After	Home	-

CVC Central venous catheter; IV Intravenous administration of therapy; HOT Home oxygen therapy; HPN Home parenteral nutrition

4.5.1 Clinical outcomes

A number of clinical outcome variables was reported for the interventions evaluated by Raisch (2003) and Nazer (2006), both of which involved aspects of intravenous home care. These outcomes are summarised in Table 26. Two common variables are reported across the studies – duration of antibiotic therapy administered through IV, both measured as the mean number of days (Raisch, 2003; Nazer, 2006). In both studies, the average duration of IV antibiotic therapy was significantly shorter in the control groups (both hospital-based treatment) compared to the intervention groups (both home-based treatment).

Table 26. Clinical outcomes in technological home care

Study	Outcome	Intervention	Control	Reported significance
Raisch (2003)	Mean (SD) number of days on IV antibiotic therapy	7.6 (2.6)	6.3 (3.1)	p=0.008
	Mean (SD) number of antibiotic days (IV and oral)	8.3 (2.7)	7.3 (3.6)	P=0.064
	Number (%) of successful episodes	72 (100)	72 (100)	
Nazer (2006)	Mean (SD) number of days on IV antibiotic therapy	19 (5.6)	16 (5.0)	p=0.001
	Mean (SD) percent change FEV_1	23 (30.0)	39 (3.7)	p=0.04
	Mean (SD) percent change FVC	17 (23.0)	24 (23.4)	p=0.10
	Mean (SD) percent change FEF_{25-75}	45 (62.8)	67 (85.5)	p=0.21
	Mean (SD) percent change FEF_{max}	29 (35.4)	52 (63.6)	p=0.10
	Mean (SD) percent change O2 saturation	2 (2.3)	1 (2.3)	p=0.53
	Weight (kg) [a.]	3 (3.0)	1 (2.3)	p=0.91

a. It is not clear from the paper whether this outcome is also reported as a mean percentage change or if it represents actual weight gain in kg.

Raisch (2003) also reports the average duration of antibiotic therapy administered orally and intravenously combined, where there was no significant difference between groups. These findings show that while the delivery of antibiotic therapy through IV alone is longer in duration for home based treatment, there is no difference in duration of anti-biotic therapy in total.

Other clinical outcomes reported by Nazer (2006) included improvements to lung function, O^2 saturation and weight, all of which were said to have improved significantly from baseline to follow-up for both groups, although follow-up values were not reported. Nazer (2006) also compared the mean percent change (from baseline to follow-up) for both the intervention and control groups for FEV_1, FVC, FEF_{25-75}, FEF_{max}, O^2 saturation, and weight, apparently using analysis of co-variance (ANCOVA). While the mean percent change in FEV_1, FVC, FEF_{25-75}, and FEF_{max}, were all lower for the intervention group compared to the control group, the only statistically significant difference was for FEV_1. The mean per cent change from baseline to follow up in O^2 saturation was higher for the intervention group but not significantly. It is not clear from the paper whether the data reported for change in weight is mean percentage change or actual change in kilograms (see Table 26). In either case, the results seem to favour the intervention group, but not at a level that is statistically significant. It is also not entirely clear what co-variates were used in the ANCOVA. The text suggests that this approach was used to control for 'baseline values' of unspecified variables (*ibid*: 746). However, initial analysis had shown that there were no statistically significant differences between the two groups at baseline on the range of outcome variables included. It is also not clear why the analysis used mean percentage change (i.e. value at follow-up minus value at baseline, expressed as a percentage of value at baseline) in measured outcomes, rather than actual change values, given the apparent comparability of the two groups.

4.5.2 Health service use

Health service use outcomes were reported in three studies reviewed in this sub-section (Raisch, 2003; Greenhough, 2004; Sturm, 2005), none of which evaluated the same model of technological care. Outcomes reported included length of hospital stay, number of clinic visits and physician visits, number of inpatient and outpatient contacts, number of GP contacts, number of community care contacts and number of clinical interventions or tests. These outcomes are summarised in Table 27.

Table 27. Health service use in technological home care

Study	Outcome	Intervention	Control	Reported significance
	Length of stay			
Raisch 2003	Mean (SD) length of stay in hospital (days)	0.1 (0.5)	6.4 (3.1)	p<0.001
	Mean (SD) length of stay in ICU	0.1 (0.5)	0 (0.1)	NS
	Mean (SD) home care stay (days)	7.1 (2.8)	2.3 (3.2)	p<.001
Sturm 2005	Mean (SD) initial length of hospital stay (days)	23.6 (18.6)	31 (25.6)	Not tested

Greenough 2004	Median (range) inpatient days	5 (0-131)	4.5 (0-282)	p=0.70
	Median (range) inpatient events per patient	2 (0-20)	2 (0-20)	p=0.47
	Clinical interventions/tests			
Raisch 2003	Mean (SD) number of microbiology studies	1.5 (0.7)	3.3 (2.3)	p<0.001
	Mean (SD) number of complete blood counts	4.4 (1.6)	6.1 (3.0)	p=0.001
	Mean (SD) number of blood cultures	1.9 (0.3)	1.7 (0.5)	p=0.004
	Mean (SD) number of cultures (all)	3.4 (0.7)	4.7 (2.0)	p<0.001
	Mean (SD) number of platelet counts	4.5 (1.7)	6.0 (3.0)	p=0.002
	Mean(SD) number of manual differentials	4.4 (1.6)	5.8 (3.0)	p=0.002
	Mean (SD) number of serum chemistries	1.0 (1.2)	3.0 (2.8)	p<0.001
	Mean (SD) number of six-pack platelet transfusions	0.7 (1.1)	0.9 (1.0)	NS
	Mean (SD) number of PRBC[a.] transfusions	0.9 (1.1)	1.4 (1.3)	P=0.015
	Mean (SD) number of TPN[b.] days	0.2 (1.5)	1.5 (2.9)	p<0.001
	Out-patient or community health service use			
Raisch 2003	Mean (SD) number of clinic visits	1.7 (1.3)	0.5 (0.5)	p<0.001
	Mean (SD) number of physician visits	1 (1.0)	6.6 (3.3)	p<0.001
Greenough 2004	Median (range) outpatient events	9 (1-30)	7 (0-41)	p=0.07
Greenough 2004	Median (range) GP contacts	12 (0-56)	15 (0-76)	p=0.012
	Median (range) community care contacts	13 (0-57)	22.5 (1-169)	p<0.001

a. PRBC Packed red blood cells

b. TPN Total parenteral nutrition

As we see from Table 27, two of the three studies reported shorter, mean initial and/or total length of hospital stay for the intervention groups. Raisch (2003) tested for statistical significance, showing that overall length of hospital stay was shorter for children suffering from low-risk, chemotherapy induced, febrile neutopenia who received home IV and other medical care, while days of home care were greater. Mean initial length of stay was also shorter for babies receiving home gavage feeding (Sturm 2005) but no statistical tests were used here. Greenhough (2004), by contrast, reported

a slightly longer median length of hospital stay for children treated by centres using high levels of HOT compared to those using low levels of HOT, but this difference did not reach statistical significance.

Raisch (2003) and Greenhough (2004) also looked at out-patient and community health service use. As Table 27 shows, the average number of clinic visits in the Raisch study was significantly greater for the intervention group, while physician visits were significantly lower. In the Greenough (2004) study, the numbers of inpatient and outpatient events did not differ significantly between groups. In addition to this, significantly fewer contacts were made with both GPs and community care services in the intervention group (Greenough, 2004).

Finally, the use of clinical interventions or tests was reported by Raisch (2003). The mean numbers of cultures, microbiology studies, complete blood counts, platelet counts, manual differentials, serum chemistries, packed red blood cell transfusions and days of total parental nutrition were all significantly higher for the control group compared to the intervention group. The mean number of six-pack platelet transfusions was also higher for the control group, but not significantly so. The only clinical test used significantly more often for the intervention group was blood cultures.

4.5.3 Costs to health services

A range of costs to health services were reported across five studies (see Table 28). Three studies based their analysis on estimated savings of acute hospital care (Stevens, 1996; Miano, 2002; Sturm, 2005). Stevens (1996) also included in an overall figure both health care costs and parents' direct and indirect costs. In all three cases, home care was reported to cost less than care as usual, but only Miano, 2002 reported any statistical testing of the difference.

Table 28. Cost to health service in studies of technological home care

Study	How assessed	Intervention	Control	Reported significance
	Overall cost of care			
Sturm (2005)	Estimated savings from reduced inpatient care (Canadian $)	$1002 per day, giving an assumed saving of $12428	-	-
Stevens (1996)	Direct and indirect costs of care for congenital dislocated hip and Legg Perthes Disease combined (Canadian $), compared with estimated costs of usual care	$68888	$193393	-
Miano (2002, 2003, 2004)	Average (range) cost per patient based on estimated savings from reduced inpatient care	2422 (150 – 30450) €	7835 (350 – 132250) €	p<0.001

	(Euros)			
Greenough (2004)	Total cost of care (including inpatient care) for babies treated in centres using high and low levels of HOT[a.]	£28965	£43555	p<0.001
	Cost of HOT only	£3619	£3142	p=0.3396
Raisch (2003)*	Median (range not reported) total charges	$5893	$9392	p<0.001
	Costs of individual elements of care			
Raisch (2003)*	Median (range not reported) cost of blood cultures	$150	$150	p=0.004 (sic)
	Median (range not reported) cost of all cultures	$200	$250	p<0.001
	Median (range not reported) cost of microbiology	$0	$0	p<0.001 (sic)
	Median (range not reported) cost of complete blood counts	$148	$198	p=0.001
	Median (range not reported) cost of serum chemistries	$81	$182	p<0.001
	Median (range not reported) cost of clinic visits	$100	$0	p<0.001
	Median (range not reported) cost of home care days	$1554	$0	p<0.001
	Median (range not reported) cost of hospital days	$0	$5460	p<0.001
	Median (range not reported) cost of antibiotics	$2523	$1526	p=0.019
	Median (range not reported) cost of platelet transfusions	$42	$84	NS
	Median (range not reported) cost of PRBC[b.] transfusions	$63	$126	NS
	Median (range not	$0	$420	p<0.001

	reported) cost of physician visits			
	Median (range not reported) cost of TPN[c.]	$0	0	p<0.001 (sic)
	Median (range not reported) cost of tests of aminoglycoside levels	$0	$0	NS
	Median (range not reported) cost of vancomycin levels	$0	$0	p<0.001 (sic)
	Median (range not reported) cost of chest x rays	£0	$0	p<0.001 (sic)
	Median (range not reported) cost of CT[d.]	$0	$0	p=0.001 (sic)
	Median (range not reported) cost of intensive care unit days	$0	$0	NS
	Median (range not reported) cost of Filgrastim	$1085	$451	p<0.001

a. HOT – home oxygen therapy.

b. PRBC Packed red blood cells.

c. TPN – total parenteral nutrition.

d. CT – commuted tomography.

Greenough (2004) and Raisch (2003) report total costs of health care (see Table 28), but with different levels of detail about the components of these costs. Greenhough (2004) calculated the costs of care using care records and a range of mean reference costs. Raisch (2003), by contrast, used charges to estimate the costs of care.

In both studies, reported total health care costs were significantly lower than the costs of routine care (see Table 28). The total cost of care in the Greenough study was significantly lower for the intervention group, when the inpatient care given to infants prior to discharge was included. When comparing the cost of HOT only, the cost of care was higher for infants cared for by centres that made higher use of HOT, as one might expect, but not significantly so.

Raisch (2003) compared the median charges for various clinical interventions and tests used by the two groups of children and these are also reported in Table 28. Because the costs reported were severely skewed, non-parametric statistical tests were used to compare median values. However, ranges were not reported, making some of the findings difficult to interpret, where identical median values have sometimes generated different test results.

4.5.4 Cost to families

Only one study examined costs to families (Stevens, 1996), but these were not reported separately from the figure for the total cost of illness.

4.5.5 Impact on families

Impact on family outcomes of HOT were reported by McLean (2000), who administered the SF-36 quality of life scale and the Impact on Family Scale to mothers, and Stevens (1996) who measured impact of home traction using the Psychological Adjustment to Illness Scale (PAIS) in both mothers and fathers of children with congenital dislocated hips and LPD. Tables 29 and 30 summarise the findings for these outcomes separately for each study.

Table 29. Impact on family outcomes in technological care at home (Stevens 1995)

Study	Outcome (Measure)	Mothers at time 3	Fathers at time 3	Reported significance
Stevens (1995)	PAIS Subscale (Health utilization)	5.70	5.10	Not reported
	PAIS Subscale (Vocational)	5.66	3.88	Not reported
	PAIS Subscale (Family)	8.40	5.30	p=0.012
	PAIS Subscale (Sexual)	6.22	2.55	Not reported
	PAIS Subscale (Extended family)	4.30	3.00	Not reported
	PAIS Subscale (Social)	9.50	7.60	Not reported
	PAIS Subscale (Psychiatric distress)	9.10	5.3	Not reported
	PAIS Total Score	47.00	32.60	p=0.051

Table 30. Impact on family outcomes in technological care at home (McLean 2000)

Study	Outcome (Measure)	Method of analysis	
		Mean (SD) adjusted difference between intervention and control groups	Reported significance
McLean 2000	Impact on Family Scale: Total Score	10.9 (4.4)	p<.05
	Social and family impact	5.5 (2.7)	p<.05
	Personal strain	4.5 (1.7)	p<.05
	Economic burden	0.4 (1.2)	NS

	Mastery	0.0 (1.0)	NS
	SF 36: Vitality	-25.8 (10.6)	p<.05
	Mental health	-19.5 (8.3)	p<.05
	Role – emotional	-32.0 (16.1)	NS
	Role – physical	-27.6 (18.1)	NS
	Bodily pain	-22.0 (11.6)	NS
	Social function	-20.4 (11.6)	NS
	General health	-18.4 (10.6)	NS
	Physical functioning	-9.7 (6.2)	NS

In the McLean (2000) study, multiple regression analysis was used to explore the discrete contribution of HOT to impact on mothers, by controlling for the chronological and gestational age of their infants, the infants' current weight, and whether the family lived in a rural or urban setting. The intervention group demonstrated significantly lower quality of life as measured by the SF 36, in two dimensions - vitality and mental health - compared to the control group. Using the Impact on Family Scale, mothers in the intervention group demonstrated significantly greater impact scores on the total score and on the social and family impact and the personal strain dimensions. This study was also able to explore the impact of HOT on mothers whose babies had received HOT in the past but no longer needed it. Simple regression analyses showed no differences in measured impact between this group of mothers and a control group whose babies had never received HOT. The researchers argue that this may indicate that the negative impact on mothers of HOT may 'be limited to the period of time when infants require active therapy with HOT' (McClean *et al.*, 2000: 442).

The Stevens (1995) study made a number of comparisons both between subjects (comparing parents of children with different types of conditions, and comparing fathers with mothers) and within subjects, examining change over time (from time 1, when children were still in hospital, to time 3 two or three weeks after they had completed home traction). For the purposes of evaluating the model of care, it is this last comparison that is important. The only significant within-subject differences that were reported were in mothers of children with LPD. They experienced significant changes in their distress in health utilisation (mean (SD) at time 1, 5.86 (3.34); mean (SD) at time 3, 7.14 (2.91), p=.022) and family functioning (mean (SD) at time 1, 7.43 (3.05); mean (SD) at time 3, 11.29 (6.04), p=0.41) dimensions of the PAIS. The researchers comment that children with LPD were older and that the mothers described them as 'difficult to entertain and resentful of being suddenly immobilized and separated from their peers' (Stevens *et al.*, 1996: 144). This may go some way to explaining their mothers' increased distress.

4.6 Home care for mental health problems

In this section, two studies (three papers) were included: Schmidt (2006), Lay (2001), and Erkohlati (2004). Schmidt (2006) and Lay (2001) both report data from a controlled before and after study of a home therapy intervention which took place over three months. The exact details of the therapy are reported in a foreign language paper, however it is known from the two papers included here that therapy was based on cognitive behaviour therapy and parent training, and was conducted by psychiatric nurses or advanced medical students over three months. During the course of the home based intervention, use of other services and treatments (e.g. outpatient treatment and pharmaceutical treatments) was allowed. Children and young people with a variety of diagnoses were included. The sample used in Lay (2001) is a subset of the larger sample in Schmidt (2006), therefore only results reported by Schmidt are included here.

Erkohlati (2004) reports on a before and after study of a home based intervention for children and adolescents with unspecified mental health conditions and, again, details of the nature of the intervention are not provided, except that it involved initial evaluation, assessment and treatment. Two individuals from unspecified but different disciplines carried out treatment.

One intervention was based in Germany (Schmidt, 2006; Lay, 2001) and one in Finland (Erkohlati, 2004). A summary of the studies is presented is Table 31. Clinical and psychosocial and behavioural outcomes are reported across these studies.

Table 31. Models of care for children with mental health problems

Study	Country	Condition	Model of care	Sample size of intervention group	Design	Primary setting	Secondary setting
Schmidt (2006), Lay (2001)	Germany	A variety of mental health problems	Home based therapy	70	Controlled before/ after	Home	Inpatient setting
Erkohlati (2004)	Finland	Unspecified mental health problems	Home evaluation, assessment and treatment	212	Retrospective review of patient data	Home	-

4.6.1 Clinical outcomes

Clinical outcomes were measured and reported in one study only (Schmidt, 2006), which assessed changes in symptoms (before and after treatment and between groups), and global treatment effects. Each of these is summarised in Table 32.

Table 32. Clinical outcomes in home care for mental health problems

Study	Outcome (Measure)	When	Intervention group	Control group	Reported significance
Schmidt (2006)	Mean (SD) symptom score (MEI Total Symptom Score)	Baseline	12.0 (5.2)	14.8 (5.4)	
		12m follow-up	4.6 (3.6)	7.5 (3.8)	p=.50
	Mean (SD) symptom improvement score as judged by psychiatrist	End of treatment	1.8 (1.0)	2.2 (0.9)	p=0.03
	Mean (SD) functioning score as judged by psychiatrist	End of treatment	1.5 (1.0)	2.0 (0.9)	p=0.01
	Mean (SD) psychosocial environment score as judged by psychiatrist	End of treatment	1.3 (1.0)	1.9 (0.9)	p=0.008
	Mean (SD) global rating of treatment effect as judged by psychiatrist	End of treatment	1.6 (1.0)	2.1 (0.9)	p=0.01

Change in symptoms was measured using the MEI (Mannheim Parent Interview), with the psychiatrist who conducted the interview rating symptom severity. Higher scores denoted greater, and lower scores weaker, symptom severity. 'Experienced child and adolescent psychiatrists' who reviewed care records at the end of treatment (but not at final follow-up) also assessed changes in symptoms, 'social adjustment' and 'psychosocial environment', and global treatment effects, all of which were defined as 'clinical outcomes'. These assessors were not aware of which model of care the child or young person had received, nor of the level of qualification of the therapists involved. Change was rated on a 7-point scale ranging from -2 (marked deterioration) to + 4 (completely improved).

The mean symptom scores from the MEI for the intervention group were lower than those for the controls at follow-up, but this was not at a level that reached statistical significance. By contrast, the symptom improvement score at the end of treatment, as judged by a psychiatrist who was not aware of where the child or young person had been treated, was

significantly higher for the comparison group than for the intervention group. This was also the case for the blinded assessments of functioning, psycho-social environment and global treatment effects. Overall, this suggests, perhaps, that the non-blinded nature of the MEI score assessment may have influenced assessment of symptom severity. Interpretation of change between baseline and end of treatment or follow-up is also complicated by the fact that the comparison (in-patient) group was assessed as more severely ill at baseline than was the intervention (home care) group. There was no apparent attempt to control for this in the statistical analysis.

4.6.2 Psychosocial and behavioural outcomes

Outcomes relating to psychosocial and behavioural functioning were reported by Schmidt (2006) and Erkohlati (2004). These are summarised in Table 33.

Table 33. Mental functioning in home care for mental health problems

Study	Outcome (Measure)	When	Intervention	Control	Reported significance
Schmidt (2006)	Mean (SD) children's global assessment score (SGKJ)	Baseline	4.5 (0.5)	4.5 (0.5)	
		12m follow-up	6.3 (1.2)	6.0 (1.2)	p=0.32
	Mean (SD) behavioural change score as judged by child	End of treatment	4.1 (0.9)	4.6 (0.6)	p=0.02
	Mean (SD) behavioural change score as judged by parent	1 year follow up	3.7 (1.1)	3.1 (1.5)	p=0.11
	Mean behavioural change score as judged by therapist	1 year follow up	3.6 (1.1)	3.2 (1.3)	p=0.16
	Mean (SD) social functioning score as rated by parents: Family	Baseline	3.8 (0.9)	3.4 (1.2)	
		12m follow-up	4.4 (0.9)	4.0 (1.4)	p=0.85

	Mean (SD) social functioning score as rated by parents: Performances	Baseline	4.7 (1.1)	4.3 (1.1)	
		12m follow-up	5.0 (1.0)	4.8 (1.2)	p=0.46
	Mean (SD) social functioning score as rated by parents: Peers	Baseline	4.0 (1.1)	3.9 (1.4)	
		12m follow-up	4.6 (0.9)	4.4 (1.1)	p=0.59
	Mean (SD) social functioning score as rated by parents: Interests	Baseline	3.8 (1.2)	3.5 (1.2)	
		12m follow-up	4.4 (1.1)	4.1 (1.1)	p=0.72
	Mean (SD) social functioning score as rated by parents: Autonomy	Baseline	4.5 (1.1)	4.6 (1.0)	
		12m follow-up	5.1 (0.7)	5.1 (1.0)	p=0.98
Erkohlati (2004)	Mean (range) psychosocial functioning score (Children's Global Assessment Scale)	Baseline	54.06 (15-82)	50.33 (20-70)	Not reported
		End of treatment	66.10 (20-92)	56.08 (40-80)	Not reported

The Schmidt (2006) study assessed global level of psychosocial functioning using the 10-point SGKJ (Global assessment scale for children and adolescents), apparently administered by the children's therapists. Higher scores indicated better functioning. Parents' subjective assessments of the child's social functioning in a number of domains were gathered, using a 7-point scale. Global assessment of the effect of treatment on behaviour was

measured using a 5-point scale where higher scores denoted improvement and lower scores deterioration. This outcome was assessed subjectively by the child at the end of treatment, and by the parent and therapist both at the end of treatment and at follow up. Psychosocial functioning was measured in the Erkohlati (2004) study, using the Children's Global Assessment Scale. There were no significant differences between groups on the SGKJ or in any of the parents' assessments of social functioning in the Schmidt (2006) study.

The subjective assessments of global treatment effects on behaviour by children, parents and therapists all indicated statistically significant differences between the home care group and the comparison group at the end of treatment (in favour of the comparison group). By follow-up after one year, however, parents' and therapists' assessments were similar for the two groups.

In the Erkohlati (2004) study, use of the Children's Global Assessment Scale suggested a higher level of change in psychosocial functioning for the intervention group (an improvement from baseline to end of treatment of 11.9 points) compared to the control group (an improvement of 5.75 points), however this difference was not tested for statistical significance.

4.7 Palliative home care

Studies of palliative care at home were not included in the previous review; this section of our report therefore extends the scope of the review on evidence of care closer to home. Three studies of palliative home care were included here: Duffy (1990), Horrocks (2002) and Surkan (2006).

All three interventions were home care for terminal illnesses and/or life limiting conditions. The Duffy model involved children with a range of neurological conditions, the majority being central nervous system tumours. Parents provided most care in the home care model, but there were also periodic visits by a palliative care nurse, 'frequent contact' from a nurse co-ordinator and medication advice from a paediatric clinical pharmacologist (Duffy *et al.*, 1990: 9). The Horrocks (2002) study was of a service established to provide nursing and psychosocial support in the community for families of children with non-malignant life-threatening illnesses. Three community paediatric nurses, and two part-time child psychologists, supported by hospital-based consultants and senior nurse managers, provided the service. Surkan (2006), by contrast, identified all children (under 17 years) in Sweden who had been diagnosed with cancer, and died before the age of 25, between 1992 and 1997. Parents who consented to participate received a questionnaire about their experiences of their child's care. Statistical comparisons were then made between children who had received home care during the last month or their lives **and** had died at home and children who died **or** were cared for in their last month of life somewhere other than home. This study was thus not about a model of care, as such, but about the care that it was possible to deliver at home to children in their last month of life.

The studies were based in Canada (Duffy, 1990), the UK (Horrocks, 2002) and Sweden (Surkan, 2006). A summary of the models is presented in Table 34. As is clear from this table, sample sizes for two of these studies were very small.

Table 34. Models of palliative home care

Study	Country	Condition	Model of care	Sample size of intervention group	Design	Primary setting
Duffy (1990)	Canada	Various	Home based palliative care	29 (14 for main satisfaction variable)	Retrospective review of patient data	Home
Horrocks (2002)	UK	Life limiting conditions	Community nursing support	16	Before/After	Home
Surkan (2006)	Sweden	Terminal cancer	End of life home care	158	Retrospective review of patient data and questionnaire comparison	Home

Note that none of these studies examined a secondary setting.

The Surkan (2006) study used both retrospective record review and questionnaires (see above for sample details). The Duffy (1990) study used a comparison group (before and after the introduction of the palliative care service) and a before and after comparison of a smaller number of parents whose children had suffered from central nervous system tumours, in relation to parental satisfaction. Horrocks (2002) used a before and after design, although the views of only 16 families were assessed at both points; another 13 families were assessed only at follow-up. Outcomes reported included satisfaction with service, which was reported in all studies, and health service use and place of death, which were reported in the Duffy paper only.

4.7.1 Place of death

Before the introduction of the palliative home care service, Duffy (1990) reports that seven out of 23 children (30%) died at home. After the service was introduced, 19 out of 26 children (73%) died at home. It is not clear over what period of time these data were gathered.

4.7.2 Satisfaction

Satisfaction was measured in each study over a number of dimensions and using a variety of formats but there were no common satisfaction measures

between them, making it impossible to perform any kind of synthesis. We therefore report the findings of each study separately (see Table 35).

The Duffy (1990) paper reported two satisfaction outcomes, but only one of these – satisfaction with health care resources received, which was measured using a 10cm visual analogue scale (VAS) – was used before and after receiving palliative home care. Higher values indicated greater satisfaction. Only 'after' values were reported (based on eight out of 14 parents surveyed), but the authors report that satisfaction was significantly higher after the programme, compared with prior to admission.

Satisfaction outcomes reported by Horrocks (2002) included information needs (along 6 dimensions), equipment needs (along 7 dimensions), respite needs (along 2 dimensions), and nursing care needs (along 2 dimensions). Each of these outcomes was measured using a Likert scale, where higher values indicated a greater need; however no further information was given regarding the range of points used on the Likert scale. The dimensions of the outcome variables were not elaborated, consequently their exact nature is unclear.

Information needs for *diagnosis*, *treatment*, *prognosis* and *services and allowances* were lower after using the service compared to before using the service, whereas information needs regarding the *cause* of the child's condition did not change. Reflecting this, the total number of families who had information needs reduced from ten to five after using the service. Equipment needs for a *hoist*, *a comfortable chair*, *a computer* and '*other*' were higher after using the service, whereas equipment need for *bathing aids* was lower after using the service. Equipment needs for *wheelchairs*, *car seats* and *beds and mattresses* did not change during the course of the intervention. The total number of families with equipment needs after using the service rose to 13, compared to ten families who reported equipment needs before using the service.

After using the service, respite needs in the home were lower whereas respite needs outside the home were greater. Nursing care needs for family provision and difficulties were both lower after using the service. These findings suggest that the palliative home care intervention reduced four types of information needs, one type of equipment need, respite needs in the home and two types of nursing care needs. With no adequate control group, it is difficult to claim these reductions as an effect of palliative home care alone. However, it seems unlikely that a palliative home care service would *not* help parents to get the information and equipment they needed to care for their child at home.

Table 35. Satisfaction in studies of palliative care at home

Study	Outcome (Measure)	When measured	Subjects	Controls	Before	After	Reported significance
Duffy (1990)	Satisfaction with healthcare resources (10cm VAS[a.])	Before and after admission to home based palliative care programme			Not reported	8.44	p<0.01 (satisfaction said to be higher after the programme)
Horrocks (2002)	Information Needs: Diagnosis (Likert Scale)	Before and 6 months after intervention			1	0	None used
	Information Needs: treatments (Likert Scale)	Before and 6 months after intervention			5	1	None used
	Information Needs: prognosis (Likert Scale)	Before and 6 months after intervention			8	2	None used
	Information Needs: cause (Likert Scale)	Before and 6 months after intervention			2	2	None used
	Information Needs: services & allowances (Likert Scale)	Before and 6 months after intervention			6	0	None used
	Total number of families with information needs	Before and 6 months after intervention			10	5	None used
	Equipment Needs: Hoist (Likert Scale)	Before and 6 months after intervention			0	3	None used
	Equipment Needs: wheelchair (Likert Scale)	Before and 6 months after intervention			1	1	None used
	Equipment Needs: comfortable chair (Likert Scale)	Before and 6 months after intervention			1	2	None used
	Equipment Needs: car seat (Likert Scale)	Before and 6 months after intervention			2	2	None used

	Equipment Needs: computer (Likert Scale)	Before and 6 months after intervention			1	2	None used
	Equipment Needs: bathing aids (Likert Scale)	Before and 6 months after intervention			2	1	None used
	Equipment Needs: beds and mattresses (Likert Scale)	Before and 6 months after intervention			0	0	None used
	Equipment Needs: other (Likert Scale)	Before and 6 months after intervention			10	11	None used
	Total number of families with equipment needs	Before and 6 months after intervention			11	13	None used
	Respite needs in the home (Likert Scale)	Before and 6 months after intervention			7	5	None used
	Respite needs outside the home (Likert Scale)	Before and 6 months after intervention			6	7	None used
	Nursing Care Needs: family provision (Likert Scale)	Before and 6 months after intervention			12	9	None used
	Nursing Care Needs: difficulties (Likert Scale)	Before and 6 months after intervention			11	6	None used
Surkan (2006)	% parents who reported their child had moderate/much access to pain relief	After child's death	97	94			OR= 2.1 (95% CI 0.5 to 9,1), p=0.3
	% parents who reported that child's pain was not relieved because of lack of staff	After child's death	12	15			OR= 0.7 (95% CI 0.3 to 0.6) p=0.4
	% parents who reported their child had access to relief of physical symptoms	After child's death	87	84			OR= 1.3 (95% CI 0.6 to 2.7) p=0.5

	% parents who reported having access to dietary advice	After child's death	69	69			OR= 1.0 (95% CI 0.6 to 1.7) p=0.9
	% parents who reported having access to relief of anxiety	After child's death	79	77			OR= 1.1 (95% CI 0.6 to 2.1) p=0.8
	% parents who reported having access to relief of other psychological symptoms	After child's death	87	79			OR=1.7 (95% CI 0,8 to 3.7) p=0.2
	% parents who had access to psychological support	After child's death	69	64			OR= 1.3 (95% CI 0.7 to 2.1) p=0.5
	% children who received medication for anxiety/ depression in month before death (reported by parents)	After child's death	23	21			OR= 1.1 (95% CI 0.6 to 2.1) p=0.7
	% children who had access to play therapy (reported by parents)	After child's death	78	80			OR= 0.9 (95% CI 0.5 to 1.7) p=0.7

a. VAS Visual Analogue Scale.

Surkan (2006) reported the percentage of parents reporting satisfaction on a number of issues, including having 'moderate or much' access to pain relief, relief of physical symptoms, dietary advice, anxiety relief, relief of other psychological symptoms, psychological support and play therapy for their children. The odds ratios of each of these needs being met were then calculated, using place of care/death as the explanatory variable. Although parents whose child was cared for and died at home were more likely to report moderate or much access to pain relief and to relief of psychological symptoms other than anxiety, the confidence intervals were too wide for the differences to reach statistical significance. No other obvious differences between the two groups were evident.

This study also reported the percentage of parents who reported that pain was not relieved because of lack of staff 'some or many times', and the percentage of parents who felt their child received medication for anxiety or depression in the month before death 'some or many times'. Again, the odds ratios for each of these outcomes suggested no significant differences between the two groups.

4.7.3 Health service use

Duffy (1990) reports that the intervention group spent significantly fewer days in hospital than the control group and a significantly smaller proportion of their time during the 'terminal phase of their illness' in hospital (Table 36). It is not clear whether both figures or only the latter, refer to the terminal phase; further, no definition of 'terminal phase' was offered.

Table 36. Health service use in studies of palliative home care

Study	Outcome (Measure)	When	Subjects	Controls	Reported significan
Duffy (1990)	Mean (SEM) days in hospital	Not stated	17.32 (4.18)	28.8 (4.77)	p<0.05
	Mean (SEM) total days of care	Not stated	131.41 (39.94)	88.11 (27.49)	p=0.37[a.]
	Proportion of terminal phase of illness spent in hospital	'Terminal phase of illness'	0.132	0.327	p<0.001

a. Calculated by us.

As might be expected, after the service was introduced, children appeared to receive a greater numbers of days of care overall. Reanalysis of these figures by us suggests that this difference was not significant statistically, but with such small numbers in the study this is, perhaps, not surprising.

4.8 Telemedicine

The previous review did not include studies of telemedicine as no evaluative literature was identified at that stage, although it was clear that this model of care closer to home for children and young people was beginning to be written about in the literature. The searches in the current review identified a number of studies assessing the use of telemedicine as a way of bringing care closer to home and preventing hospital admission. Four studies were included in this new category, (Dick, 2004; Miyasaka, 1997; Romano, 2001; Young, 2006). Two papers about the same service (Dick, 2004; Young, 2006) appear to be part of a single evaluation. We also found an earlier paper (Young, 2004) associated with this study that had explored what a 'core model' of tele-home care for transition from hospital to home should look like.

Two studies (one service) were conducted in Canada (Dick, 2004; Young, 2006), and one each in Japan (Miyasaka, 1997) and the USA (Romano, 2001). A summary of the studies is in Table 37.

Table 37. Models of telemedicine

Study	Country	Condition	Model of care	Sample size of intervention group	Design	Primary setting	Secondary setting
Young (2006)*	Canada	Complex health conditions requiring clinical support at home beyond scope of normal home care services	Audio/video conferencing and remote vital signs monitoring	63 (10 excluded from analysis as they were recruited during initial 'run-in' phase of service	Before/After (with a comparison group)	Home	Community Care Access Centres
Dick (2006)[a.]	Canada	Serious, chronic conditions with co-morbidity	Video conferencing	67 (10	Started as RCT, converted to uncontrolled because of family preference for home care	As above	As above

Miyasaka (1997)	Japan	Various, with need for respiratory care	Videophone	7	Before/ After	Home	Hospital
Romano (2001)	USA	Asthma	Satellite telemedicine link between school health centre and University Health Sciences Centre	17	Before/ After	Home	-

a. Same care closer to home service.

The specific type of technology used for bringing care closer to home differed across the studies but all involved some form of visual link between children and/or their families and health professionals. The service evaluated in two studies (Young, 2006; Dick, 2004) used videoconferencing to maintain contact between medical professionals at hospital sites and the families of children with complex health conditions, to enable them to be discharged home. Another used a videophone to enable monitoring of children dependent on home respiratory care (Miyasaka, 1997) and the third involved monitoring children with asthma who attended a school health clinic in a remote area, via a satellite link to a university health centre (Romano, 2001). There was little further information about the use of the technology, with each study noting only that it formed part of a care plan where the objective was to prevent hospital visits by replacing face-to-face contact in the hospital with some form of information and communication technology.

Only one study, Romano (2001) assessed telemedicine for a single condition group – asthma. The other studies assessed telemedicine in relation to broader condition groups and care needs, although all children had complex and/or long-term conditions that required monitoring.

All four studies used some form of before and after design, with the Young study also making comparisons with a group who received 'traditional community-based home care and physician services' (Young *et al.*, 2006: 665). The comparison group was not equivalent to the intervention group in the important respect of being able to go home supported only by traditional community health care support. Analysis in the Young study also distinguished between two subgroups of children and young people receiving tele-home care – those with no readmissions and those with multiple readmissions to hospital whilst using the service. The children with multiple readmissions were more likely to be receiving mechanical

ventilation at home (13% compared with none in the other groups) and less likely to have a chronic condition (69% compared with 77% in the no readmission group and 100% in the comparison group).

The Dick (2006) study started out as an RCT but the design was changed to an uncontrolled trial, reporting only before and after data, because of the strong preference expressed by parents for the home care service and their withdrawal from the trial after randomisation to the usual care group.

Miyasaka (1997) assessed use of a range of health care resources by seven families who received the videophone service while already receiving home care for their child, comparing the six months before and six months after the videophone was installed. Data for three children who were discharged home with a videophone from the outset were also available for the six months following discharge.

Outcomes reported included mortality (Young, 2006), clinical (Romano, 2001), health service use (Miyasaka, 1997), satisfaction (Dick, 2004), quality of life (Romano, 2001; Young, 2006), and impact on the family (Romano, 2001; Young, 2006).

4.8.1 Mortality

Although not specified as a formal outcome, the Young (2006) study does report the numbers of children surviving to six months after recruitment to the study. There was a mortality rate of 12 per cent (n=2) for intervention subjects in the multiple readmission subgroup, compared to no deaths in the no readmission intervention group and none in the comparison group. A statistical comparison was not used for this outcome, as is appropriate given the lack of comparability between the groups.

4.8.2 Clinical

The single study reporting clinical outcomes (Romano, 2001) included the mean number of symptom free days, mean symptom scores, the number of patients with seven free symptom days and forced expiratory volume (FEV_1), all of which were measured at the start of the intervention and again at 24 weeks. These outcomes are presented in Table 38. All results suggest positive change over time for those receiving the telecare service, but without a control group it is difficult to know whether this change is simply a result of time or whether it is different from what might have been achieved given a different care model.

Table 38. Clinical outcomes in telemedicine

Study	Outcome (Measure)	Baseline	24 weeks	Reported significance
Romano (2001)	Mean (SD not reported) number of symptom free days	2.35	4.31	p<0.05
	Mean (SD not reported) symptom score	2.31	1.31	p<0.001

	Number of patients with 7 symptom free days	1	9	p<0.002
	FEV_1	Not reported	A 6% mean increase at week 24	Reported as NS

4.8.3 Health service use

Health service use outcomes explored in Miyasaka (1997) included the number of unscheduled visits to hospital, the number of hospital admissions and the number of days spent hospitalised, all of which were measured for seven children in the six months before installing the videophone and for six months after (Table 39). The number of unscheduled visits to hospital, hospital admissions and days spent hospitalised all decreased following the telemedicine intervention, although only the reduction for the number of unscheduled visits was reported as statistically significant. By contrast, as might be expected, the number of tele/videophone calls made increased substantially after installation of the videophone.

Table 39. Health service use in telemedicine

Study	Outcome (Measure)	6 months before introduction of videophone system	6 months after	Reported significance
Miyasaka (1997)	Number of telephone calls	11	58	p<0.004
	Number of unscheduled hospital visits	24	5	p<0.01
	Number of hospital admissions	4 (three patients)	2 (two patients)	NS
	Number of days hospitalised	22	10	Not reported

4.8.4 Satisfaction

Both parent preferences and satisfaction were measured in the Dick (2004) study, using, respectively, a 10cm visual analogue scale (VAS) and a 20 question questionnaire that generated a 100 point rating scale (see Table 40 for results). Positive preference scores on the VAS indicated a preference for telehome care (THC) and negative scores indicated a preference for hospital care. For the 100 point satisfaction rating scale, higher scores denoted greater satisfaction. Preference was measured at baseline and then at eight weeks, whereas satisfaction with both hospital care and THC was measured at eight weeks only.

Table 40. Satisfaction in telemedicine

Study	Outcome (Measure)	Baseline	8 weeks	Reported significance
Dick (2004)	% reporting very strong preference for telehome care	59	71	Not tested
	Mean (SD) preference score for telehome care	3.25* (SD not reported)	4.47 (1.07)	p<0.0032
	Mean (SD) satisfaction score	-	83.1 (10.3)	-

** Read from graph by us.*

There was a significant increase in preference for THC at eight weeks compared to baseline. Satisfaction scores for care overall were high, and sub-scale analysis of satisfaction with hospital care and with THC showed little difference between the modes of care (mean 83.5, SD 13.2 and mean 82.8, SD 13.3 respectively). Further analysis of these measures showed that preference for THC before the child was discharged was not significantly correlated with actual satisfaction (Spearman rho = 0.24, p=0.1341), whereas preference for THC after the child had received the service was positively correlated with higher scores on the THC domain of the overall satisfaction scale (Spearman rho = 0.36, p = 0.0396).

The authors report that parents of children who were heavily technology dependent had 'a relatively higher satisfaction with hospital care versus home care' (Dick *et al.*, 2004: S-52) but do not report data or statistical testing for this assertion.

4.8.5 Quality of life for children and young people

Quality of life was measured for children and young people in two studies (Young, 2006; Romano, 2001) using newly developed tools in the Young study and a paediatric quality of life measure for children with asthma (cited as Juniper *et al.*, 1996) in the Romano study. There is little information in either paper about the nature of the measurement, the scoring system, or about what the values denote.

In the Romano study, quality of life was measured at baseline, and at weeks 4, 12 and 24. There was little obvious change between baseline and week 12, but then an increase between weeks 12 and 24, which contributed to a reported overall significant increase in measured quality of life from baseline to 24 weeks (Table 41). Mean values have been read by us from the graphs in the paper; no means, SDs or other indications of variability were reported by the authors.

Table 41. Quality of life in studies of telemedicine

Study	Outcome (Measure)	Baseline	24 weeks	Reported significance
Romano (2001)	Mean quality of life (child)	5.25*	5.75*	p<0.01
Young (2006)	Time series analysis of change in quality of life scores	See main text		

** Values estimated by us from graph.*

The Young (2006) study used a time series approach to measure the mean change in quality of life scores at the point of transition from hospital to home, during the intervention and then at discharge from the intervention. The reported analysis distinguishes between the THC groups with and without multiple readmissions and the group receiving standard community care. The authors state that they did not intend to test differences between groups because of the small samples involved.

The paper does not report direct values, so the trends evident in the graph provided by the authors are described here. Quality of life for the children started and remained the highest for the THC sub-group that did not have multiple readmissions. Measured quality of life for the THC sub-group that had multiple admissions and the comparison group was similar over the measurement period, however all three groups showed nearly the same level of quality of life at final follow up at eight weeks after baseline.

4.8.6 Impact on family

Only one study (Young, 2006) examined family impact, per se. This was measured using the Impact on Family scale (cited as Stein and Riessman, 1980). Results are reported in the form of graphs and analysis is said to have used time series methods. As in other part of the Young study, results were reported separately for TCH children with and without multiple readmissions and for the comparison group who received standard care.

The graph in the paper shows that the THC sub-group with multiple readmissions had the highest score for impact on family at baseline, that this increased over the measurement period and was the highest of the three groups at final follow-up. The THC sub-group without multiple readmissions had the second highest impact score at baseline; this fluctuated slightly over time, and ended up slightly lower than at baseline, but was still the second highest at final follow up. The comparison group had the lowest impact score at baseline, which declined up to five weeks after baseline and then rose slightly up to final follow up. However, it remained the lowest of the three groups, as might be expected given the lower overall condition severity of this group of children. The authors argue that because the trajectories for both THC groups were similar, this 'may suggest that the THC service was particularly effective in … reducing the

impact on family of those children who were expected to have multiple admissions'(Young *et al.*, 2006: 668). They also suggest that the similarity between the THC sub-groups and the standard care comparison group 'suggests that the THC service reduced the impact on family …' (*ibid*). With no statistical results presented in the paper it is difficult to assess whether this is the case or not.

Young (2006) and Romano (2001) also explored parental quality of life (QoL). Romano does not report what QoL measure was used, and the Young study measured parental QoL with a new tool developed specifically for the study.

Parents in all three groups analysed in Young (2006) started with similar QoL scores at baseline. No data or statistical tests are reported directly, but time series graphs are presented. Both THC groups and the comparison group improved their score over time up to two to three weeks after baseline, although those whose children were in the THC no readmissions group (see above) appear then to have improved more rapidly than those in the other groups. At around two and a half weeks the comparison group scores began to pull away (improve) from those of the multiple readmission THC group, but by the end of follow-up, at eight weeks after baseline, their scores appear to have been similar. Overall, the groups without multiple readmissions ended with the highest QoL scores. It is difficult to interpret the authors' commentary on these trends because they do not distinguish between the results for children's QoL (see above) and parents' QoL.

Romano (2001) reports a statistically significant improvement in parents' measured QoL from baseline to 24 weeks (means of 5.1 and 6.3 respectively, read by us from a graph, with a reported p value of <0.002). No data are reported directly, there is no mention of the size of standard deviations, and it seems possible from the text that not all parents who completed the QoL measure at baseline also completed it at 24 weeks.

4.9 Admission avoidance and early discharge

Admission avoidance services (where children and young people who are ill are diverted from admission to a hospital ward overnight) can be predominantly home-based, where care that would otherwise be provide in hospital is provided at home, usually including triage via a hospital-based assessment unit. Alternatively, care can be provided in a short-stay facility that is separate from a normal paediatric ward. For this section of the review, we found examples of both and analysed them separately.

4.9.1 Predominantly home-based admission avoidance

One study, different aspects of which were reported in three papers, evaluated a hospital at home (HaH) service designed to prevent hospital admission (Davies, 2003; Dale, ND; Wild, 2000). Children who lived in Rugby (UK) who presented with an acute illness at a paediatric assessment unit, at an acute A&E department or to their GP could be referred to the HaH service. The HaH team leader on-call then triaged the referral and, if

appropriate, allocated a HaH nurse to the child. Further details of the nature of the intervention are reported in Chapter 5 (descriptive).

The original intention had been to carry out a before-and-after comparison of service use, and to have a case-controlled evaluation. Changes in service configuration in the area being studied, while the research was underway, made this impossible. The study was therefore carried out in two phases; phase 1 compared acute paediatric service use 'pre-implementation' with that during an 'interim' stage, after some acute paediatric beds had been closed. Phase 2 then compared statistics from the 'interim' stage of phase 1 with those from after the HaH service had been implemented.

We confine ourselves here to reporting data from the 'interim' stage of phase 1 and/or the post-implementation stage of phase 2. When comparisons were made, they were between children from Rugby who presented at the assessment unit and/or were admitted to hospital for acute care in a seven-month period (August to February) 'interim' phase prior to the establishment of the intervention, and those who presented in a nine-month period (June to March) after the service had been introduced.

Data about children's, families' and GPs' views of the HaH service and of in-patient acute hospital care were also collected. Record review of a proportion of the children who had been referred to the HaH service examined issues of patient safety and access to specialist care.

The study is summarised in Table 42.

Table 42. Models of predominantly home-based admission avoidance

Study	Country	Condition	Model of care	Sample size of intervention group	Design	Primary setting	Secondary setting
Davies (2003); Dale (ND); Wild (2000)	UK	Various (Acute)	Hospital at home	324 referred to hospital-at-home in phase 2 study	Before and after with a case-control comparison	Home	-

Clinical outcomes

Clinical outcomes were assessed for a proportion of children who had presented to the admissions unit, been admitted to the in-patient ward or had used the HaH service, using retrospective review of GP records to track care pathways and adverse events. The overall conclusion of the researchers was that there was no evidence of delays in access to specialist care as a result of referral to the HAH service, nor were there any reports of adverse events or complaints about delays in access to specialist care. Some children were referred on from HaH to acute care and record review concluded that these referrals had been appropriate.

Health service use

Reported health service use included the number of children presenting at the paediatric admission unit, the number admitted to hospital, (by age group and by diagnostic category), length of stay and readmissions. For some of the outcomes (admissions by age group, disposal and diagnostic category), direct values were not reported but displayed graphically. Further, some of the percentage figures given in the text do not tally with figures given in subsequent tables. This may be due to missing data, but this is not made clear in the tables or the text. Tests of significance were not reported routinely, but are mentioned in a few places. We assume that only statistically significant results were reported, but this is not clear from the text.

The text (Dale, ND, executive summary) suggests that there was a fall of 5.9 per cent in presentations at the admission unit between the two phases (from 495 separate referrals to 466). In fact, figures presented in Table 3 in the report (p.22) suggest a slightly greater fall, from a total of 505 presentations in phase 1.[f] A small change in admission to an in-patient ward also took place; in phase 1, 51 per cent of children attending the admission unit were admitted compared with 44 per cent in phase 2 (*ibid*: 24). Overall, the reduction in inpatient admissions is claimed in the executive summary to be 19.6 per cent across the seven months, from 264 children before the service was introduced, to 212 after. These figures do not tally with those in Table 4 in the report (p.26) where disposal figures are reported by severity of the child's illness. We assume this is because this table does not report the extent of missing data.

The age distribution of children referred to the assessment unit remained broadly the same, but there were changes in the numbers admitted from the unit to in-patient care, with younger children being less likely and older children more likely to be admitted. This was reflected in the overall mean age of 4.2 (median 24 months) for those admitted in phase 1 and 5.8 (median 42 months) for those admitted in phase 2.

Admission from the assessment unit to in-patient care fell between phases 1 and 2 for a number of diagnostic groups: infection/parasitic, respiratory, injury/poison, digestive and 'other'. By contrast, there was an increase in admissions in the neoplasm, haematological, mental disorder, nervous system, circulatory, genitor-urinary, skin, metabolic and ENT diagnostic groups. There were no observed differences for diagnostic groups related to congenital abnormality, perinatal and musculo-skeletal.

The severity of illness of children admitted from the assessment unit to an in-patient ward, as assessed by a standardised instrument, changed between phases 1 and 2. The proportion rated as 'mildly ill' fell (from 57% to 43%), while the proportion rated as having a 'medium type illness' rose (from 26% to 34%). A p value of <0.01 is reported here but it is not clear what comparison was being made, nor which test was used.

[f] By our calculation, the numbers given for children with one or more referrals in phase 2 sum to 466 separate referrals; the numbers for phase 1 sum to 505.

Length of stay for children admitted to an in-patient ward decreased from an average of 2.13 days in phase 1 to 2.03 days in phase 2, with a median of 1-2 days in both. The text in Day (ND, p.31) claims that the rate of re-admission showed no change between phases 1 and 2. In fact, Table 5 in the report suggests that the proportions of children who were admitted again after their initial admission increased from 9.4 per cent in phase 1 to 10.6 per cent in phase 2. This contributed to an average number of admissions per child of 1.08 in phase 1 and 1.13 in phase 2 (calculated by us from figures in Table 5, Day ND).

None of the changes reported above is major, but together they suggest that having the HaH service allowed younger, less severely ill children, with less complex conditions, to be diverted away from in-patient admission. As a corollary, in-patient admission was increasingly used for somewhat older children with more severe and complex conditions.

Impact of the episode of illness

A questionnaire to parents was used to assess a range of views about and levels of satisfaction with hospital in-patient care and HaH care. The research team experienced difficulty recruiting parents in either setting, though there was a higher response rate from those whose child had been an in-patient compared to those who had used the HaH service.

The summary at the end of the relevant chapter (Day, ND: 59) suggests that parents were asked whether the *episode of illness* had had any adverse effect on their child. By contrast, the main text suggests that parents were asked 'whether they felt that there had been any adverse effects on the child … as a result of … admission to hospital or HaH' (*ibid*: 45). These are clearly not the same thing, and in the absence of a questionnaire in the appendices of the report, it is impossible to know which was actually asked.

Of parents whose child had been admitted as an in-patient, 80 per cent in phase 1 and 74 per cent in phase 2 reported that there had been no adverse effect on the child. A higher percentage of parents whose child had received HaH (91%) reported no adverse effect. The researchers report that this difference is statistically significant. However, given our comment above and that, as we saw earlier, introduction of the HaH service meant that children who eventually became in-patients tended to be more ill and with more complex conditions than had been the case before the service was introduced, it is difficult to know how to interpret this finding.

Impact on family

Parents were also asked about any effect on the family arising from their child's episode of illness. A significantly higher percentage of parents whose child had received HaH (89%) reported that there had been no adverse effect on the family, compared with 71 per cent of parents whose child had been admitted in phase 1 and 74 per cent of those whose child had been admitted in phase 2. These differences are reported as statistically significant but, again, it is difficult to interpret their meaning.

Costs to family

Three elements of costs to family were reported.

The first was the proportion of parents reporting extra costs for caring for other family members while their child was receiving care, either in hospital or in the HaH service. The summary of the relevant chapter and the main text do not agree about the findings here. The main text says that no HaH parents reported such costs, while 28 per cent of phase 1 and 24 per cent of phase 2 parents whose child had been admitted to in-patient care did (Day, ND: 47). By contrast, the summary (*ibid*: 59) states that 19 per cent of parents whose child had received HaH reported extra costs for caring, compared to 33 per cent of those whose child was admitted to in-patient care in phase 1 and 76 per cent in phase 2.

Secondly, parents were asked whether their child's episode of care had affected their working arrangements. Here the summary and main text agree: 41 per cent of those whose child had received HaH compared to 52 per cent of phase 1 and 51 per cent of phase 1 parents whose child had been admitted to in-patient care reported an adverse effect. This difference is reported as not statistically significant (p value of >0.05).

Finally, parents were asked about out of pocket expenses incurred while their child was ill. This outcome is not summarised, and the main text is confusing. However, what appears to be the case is that seven per cent of HaH parents reported out of pocket expenses compared to 38 per cent (text says 385, but we have assumed this is a typographical error) of phase 1 and 23 per cent of phase 2 parents whose child had been admitted to in-patient care.

Costs to health service

Costs to the health service were calculated for phases 1 and 2, using cost per bed day for acute hospital admission and the total number of day beds occupied by children from Rugby. Costing was bottom-up for in-patient care, and the costs of the paediatric assessment unit were based on an average of 1.5 hours of the cost per bed day. In phase 2, the costs of the HaH service (mainly staff costs) were also calculated.

Over seven months in phase 1, the total cost of acute hospital, in-patient and assessment unit care for Rugby children was £106,352 and over seven months in phase 2 it was £82,205.

The total costs of the HaH service over 12 months were calculated to be £162,581. Based on this, the researchers calculated that the costs of the service over the seven month, phase 2, period would have been £94,431.

Using all the above figures, the total cost of care for Rugby children over 12 months in phase 1 was estimated as £183,106 and over 12 months in phase 2 as £304,114, representing a 66 per cent rise in overall costs. However, a number of acute paediatric beds had been removed prior to the phase 1 'interim' stage. Taking these into account, the researchers claim (but do not demonstrate) that the annual costs in phase 2 were nonetheless

£200,000 less than those three years previously, when the additional acute beds had been in place.

4.9.2 Predominantly hospital-based admission avoidance

In this category, six studies (seven papers) were included, two of which (Browne 1996, 2000; Blair, 2004, 2008) studied the same service at different periods (Table 43). In the later Browne study, the data about the short stay ward reported in Browne (1996) was amalgamated with that from another short stay ward in a different hospital. All the services studied were in some way based on a short stay facility in a hospital where the objective was to prevent admission to an in-patient ward. The terminology for the services differed, but they all operated on the same principle. They included a children's emergency annexe/short stay ward (Browne, 1996, 2000), assessment units (Beverley, 1997; MacLeod, 2002), an observation unit (Gouin, 1997) and a paediatric ambulatory care unit (Blair, 2004, 2008). The interventions described by Blair (2004, 2008) and Beverley (1997) are also included in our descriptive review, see Chapter 5.

All the studies used data collected retrospectively through service audits, and compared data from the period prior to introduction of the service to data gathered afterwards. Blair (2004, 2008) also compared the experiences of parents using an ambulatory care unit with those using the A&E department in the same hospital, when the ambulatory care unit was closed at night. Three studies were in the UK (Beverley, 1997; Blair, 2004, 2008; MacLeod, 2002), two in Australia (Browne, 1996, 2000), one in Canada (Gouin, 1997).

All the interventions targeted children presenting to A&E departments, but inclusion and exclusion criteria varied between studies and, as a result, the nature and severity of condition in the samples varied. However, all studies dealt with children whose needs could be classed as acute, and some included surgical as well as medical cases (see Table 43). The only study with a single condition focus was Gouin (1997) which focused solely on an observation unit for children with acute asthma.

Table 43. Models of admission avoidance in hospital settings

Study	Country	Condition	Model of care	Sample size of intervention group	Design	Primary setting	Secondary setting
Beverley (1997)	UK	Miscellaneous (acute medical and pre-surgical)	Day assessment unit	3276	Retrospective review of patient data	Hospital	-
Browne (1996[a.])	Australia	Miscellaneous (acute medical and surgical)	Children's Emergency Annexe (short stay	1300	Prospective collection of patient data	Hospital	-

			ward)				
Browne (2000)[a]	Australia	Miscellaneous (acute medical and surgical)	Short stay ward (as above) plus additional short stay ward in another hospital	6248	Prospective collection of patient data	Hospital	-
Blair (2004, 2008)	UK	Miscellaneous (acute, not clear)	Short stay ambulatory unit	104	Comparison between users of unit and those using A&E 'out of hours'	Hospital	-
Gouin (1997)	Canada	Asthma	Observation unit	350	Retrospective review of patient data	Hospital	-
MacLeod (2002)	Northern Ireland	Miscellaneous (acute medical only)	Assessment unit	Not reported	Retrospective review of patient data	Hospital	-

a. Same service included in both studies.

Outcomes reported in the studies of admission avoidance in hospital settings included health service use, costs to health service, satisfaction and impact on family.

Health service use

Health service use was measured using a range of outcomes including admission rates, length of stay, referral rates, rates of day case patients and (further) visits to A&E departments. Table 44 summarises the data reported.

Table 44. Health service use in admission avoidance in hospital settings

Study	Outcome (Measure)	When	Before	After	Reported significance
Beverley (1997)	Total emergency admissions for children	1 year prior to and 1 year after the establishment of the assessment unit	2525	2737	-
	Number of emergency paediatric admissions (% of total emergency admissions)	As above	1650 (65)	2016 (74)	-
	Number (% of total emergency paediatric admissions) of emergency overnight paediatric admissions	As above	1489 (90)	1443 (72)	-
	Number (% of total emergency paediatric admissions) of paediatric patients with LOS <1 day	As above	498 (30)	734 (36)	-
	Number (% of total emergency admissions) of emergency surgical admissions	As above	875 (35)	721 (26)	-
	Number (% of total emergency surgical admissions) of emergency overnight surgical admissions	As above	685 (78)	636 (88)	-
	Number (% of total emergency surgical admissions) of surgical patients LOS <1 day	As above	319 (36)	265 (37)	-
Browne (1996)	Mean (total for study period) yearly admissions to in-patient bed[a.]	Four years before study and 12 m after implementation of first short-stay ward	5315 (mean)	4766 (total)	p=0.0072
Browne (2000)	Number of admissions to in-patient bed[b.]	12 m before and 12m after implementation of second short stay ward	8065	6873	-
Blair (2004)	Number of admissions to in-patient bed Sept to Dec	In year before implementation of ambulatory care unit and in third year of operation	682	515	p=0.0007

	% of children <2 years admitted as in-patients for less than 24 hours	As above	49%	40%	p=0.015
	% of children admitted who were <4 years	As above	72%	58%	Not reported
	Number (%) of transfers to other hospitals	As above	44 (0.08%)	9 (0.02%)	Not reported
	% of 'longer ward stays' (not defined)	Not reported	Not reported	Not reported	p=0.08
Gouin (1997)	Number of 'asthma visits' to A&E	Between 13 and 24 months before and 12 months after the establishment of observation unit (OU)	1979	2248	
	Admission rate to in-patient care (%)	As above	31	24	p<0.01
	% of children hospitalised for <24 hours	As above	17	10	p<0.01
	Rate of repeat visits to A&E within 72 hours of discharge %	As above	3.2	5.0	p=0.01
MacLeod (2002)	Numbers and % change in paediatric in-patient admissions for children <15 years in relevant post-code area	One year before and three years following implementation of ambulatory assessment unit	1335 (0)	705 (-47.2%)	-

a. Text is confusing. Data given as mean number of admissions, but text refers to significant reduction in bed days (p.311).

b. Data for the first short-stay ward in this paper are the same as those presented in Browne (1996), so are not repeated here.

Only one of the included studies reported findings in the context of overall activity in A&E departments (Gouin, 1997). This shows a clear impact on admission rates for children attending an A&E department because of asthma. However, repeat visits to the A&E department within 72 hours of discharge increased significantly over the same period. As a corollary to diversion from in-patient care, the proportion of children who were admitted for fewer than 24 hours fell significantly.

The other studies reported findings only in relation to change in the *numbers* of in-patient admissions, with some also reporting proportionate change in the nature of those admissions (for example, overnight stays, stays of less than 24 hours and so on). With no information on total A&E activity, it is difficult to judge whether the services introduced had diverted a higher proportion of children away from in-patient care.

Two studies do demonstrate apparent impact on the nature of admissions. Beverley (1997) shows a shift in overall admissions, with paediatric (medical) admissions accounting for a higher, and surgical admissions a lower, proportion of all emergency admissions after a day assessment unit was introduced. In medical emergency admissions, a smaller proportion involved overnight stays and stays of fewer than 24 hours after the unit was established. By contrast, the proportion of emergency surgical admissions that involved overnight stays increased, while the proportion requiring stays of fewer than 24 hours remained almost the same. None of these changes was tested for statistical significance.

Blair, in a very short abstract (Blair *et al.*, 2004) reports a reduction in the numbers of children being admitted to in-patient beds after the implementation of an ambulatory care unit. Within that, reductions in the proportion of children under the age of two admitted as in-patients for fewer than 24 hours, of the proportion of children admitted who were under four years of age, and of the proportion of children transferred to other hospitals are also reported.

MacLeod (2002) and Browne (1996, 2000) report reductions in the numbers of children being admitted as in-patients, after the introduction of, respectively, an ambulatory assessment unit and a short stay ward.

Costs to health service

Costs to health services were reported by both Browne (2000) and Beverley (1997).

Browne (1996, 2000) reports the potential cost savings of the ambulatory unit based on fewer bed days resulting from the intervention. In 1996, the estimated cost savings from having a short stay ward in one hospital was based on a difference in 'bed cost' between hospital and the short stay ward of A$250, with a total estimated saving of 'up to' A$500,000 (Browne *et al.*, 1996: 311). It is not clear from the text exactly how this figure was arrived at. In 2000, the estimated cost saving of the short stay ward in the second hospital was based on the reduction in bed days at a cost of $231 per bed day, with an estimated potential saving of A$2383138.80 over two years

(Browne, 2000). Again, it is not entirely clear how this savings figure was calculated.

Beverley (1997) reports a reduction in staffing costs in children's wards from £680,192 in the year before the establishment of the ambulatory unit to £648,063 one year after and a projected cost of £642,062 the following year, 'despite an increase in the emergency admissions of 8.4 per cent' (Beverley *et al.*, 1997: 290).

Satisfaction

Only one study examined satisfaction with admission avoidance services in hospital settings, via a questionnaire for parents of children using the ambulatory care unit over a period of three months. This part of the evaluation of the unit was reported in Blair (2008).

Over a one-month period, parents attending A&E with their child when the unit was closed (between 10.00pm and 9.00am) also completed the questionnaire about their experiences. It is not clear from the text whether the month in which the comparison group of parents was surveyed was during the three months that parents whose children used the ambulatory unit were surveyed. The proportion of parents attending the unit who were offered questionnaires was low (33% by our calculation) and of these only 70 per cent responded, meaning that only 31 per cent of eligible parents were surveyed. It is not clear how many parents in the A&E study were eligible for the study, but of the 60 who received a questionnaire 41 (68%) responded. The two groups were not equivalent; parents attending out of hours were significantly more likely to be fathers, to be from minority ethnic communities, and not to have English as their first language. The researchers claim that none of these differences influenced the overall satisfaction variables.

Three variables seem relevant to parental satisfaction: ease of access to the service, being very satisfied with the service, and expectations having been met. Values for the latter two outcomes were not directly reported and have been read from the graph in the paper (Table 45). Parents using the ambulatory unit were significantly more likely to feel very satisfied with the service, and that their expectations had been met, than parents using A&E. At the time of presentation to the unit, 88 per cent of parents felt access was easy, whereas 95 per cent of parents presenting at A&E felt that access was easy; this difference did not meet the level of statistical significance of $p<0.05$ set by the researchers.

Table 45. Satisfaction in admission avoidance in hospital settings

Study	Outcome (Measure)	When	Intervention	Controls	Reported significance
Blair (2004, 2008)	% parents reporting ease of access	At time of presentation to either assessment unit	88	95	p=0.058

		or A&E during study period			
	% of parents feeling very satisfied with service[a.]	As above	51	31	p=0.03
	% of parents feeling that expectations had been met[a.]	As above	81	64	p=0.049

a. Read from Figure 1, Blair 2008.

Impact on family

The Blair (2008) study was also the only one to explore impact on the family, using difference in parental anxiety between those attending the ambulatory unit and those attending A&E, and difference in parental anxiety before and after using either service. Parental anxiety was based entirely on self-report and not on use of a validated measure.

There were no significant differences between those using the unit and A&E in self-reported parental anxiety either before or after presenting. As one might expect, there was a significant reduction in parental anxiety in both groups after using both the ambulatory unit and A&E. It seems from the figures presented that parents attending A&E experienced a greater percentage reduction in anxiety (from 63% anxious before and 5% after presentation) compared with those attending the ambulatory unit (55% anxious before and 13% anxious after). However, this difference in change was not tested statistically.

4.9.3 Early discharge services

Two studies were included in this category, where models of care primarily involved a care package designed to facilitate early discharge of patients. The models varied slightly, with one early discharge service for children with a range of long-term or complex conditions managed from an acute hospital base (Bergius, 2001) and one dedicated discharge co-ordinator and a clinical pathway for children who were dependent on respiratory technology (Tearl, 2006). One study was in Sweden (Bergius, 2001) and one in the USA (Tearl, 2006). Both studies made comparisons of some sort; in Bergius this was limited to a comparison of bed days and costs with in-patient care, and in Tearl (2006) a comparison of patient data before and after the discharge co-ordinator was in post. Tearl also reported equipment providers' views of the readiness of the family for the child's discharge. A summary of the included studies is in Table 46.

Table 46. Models of early discharge care in the home

Study	Country	Condition	Model of care	Sample size of intervention group	Design	Primary setting	Secondary setting
Bergius (2001)	Sweden	Complex and/or long-term	Computer and mobile phone technology (not otherwise described)	Not stated	Retrospective review of patient data	Home	Hospital
Tearl (2006)	USA	Respiratory	Dedicated discharge coordinator and clinical pathway	49	Retrospective review of patient data	Home	Hospital

Health service use

Health service use outcomes included length of hospital stay (Tearl, 2006) and number of bed days at home rather than in hospital (Bergius, 2001). These outcomes are summarised in Table 47. In the Tearl study, length of hospital stay was reduced, but not to an extent that reached conventional levels of statistical significance. All that is reported in Bergius (2001) is that 300 hospital bed days were saved during 350 'care events' (p.S1:33).

Table 47. Health service use in early discharge in the home

Study	Outcome (Measure)	When	Before	After	Reported significance
Bergius 20001	Bed days	During first full year of operation of home-care service	Not reported	Said to be 3000 bed days at home instead of at hospital	-
Tearl (2006)	Mean (SD) length of hospital stay	18m before and 18m after discharge co-ordinator was in place	82 (45)	48 (44)	p=0.06

Cost to health service

Bergius (2001) reports that an unpublished evaluation of the home care service showed that it was 'cost-effective' (p.S1:33), being 'at least 30 per cent cheaper than the equivalent care' in the children's hospital from which the children had been discharged. It is not clear how the calculation was done to arrive at this conclusion, but the paper refers to the home care service's lower staffing and premises costs.

Impact on family

Tearl (2006) asked the companies who provided equipment to the homes of families of children with respiratory conditions how satisfied they were with the quality of training that families had received and, thereby, the families' readiness to care for their technology-dependent child at home. After the discharge co-ordinator was in post, there was a significantly higher proportion of reports of no deficiencies in family preparation (92%) compared to before (48%).

4.10 Discussion and conclusions

The findings reported both in this chapter and Chapter 3 (trials) will be discussed in more detail in Chapter 7, however a short discussion of the evidence reviewed in this chapter is provided here.

The type and range of evidence reported here clearly favours outcomes regarding costs, with eight out of the nine clusters containing some kind of costing outcome. This is at the expense of outcomes of clinical effectiveness which were reported for six out of the nine clusters. Quality of life outcomes, which are often neglected in RCTs in favour of other outcomes, were reported in seven of the nine clusters here.

Despite the fact that outcomes were reported for clinical effectiveness, health service use, costs and quality of life, there was still a limited amount of evidence in many of the above clusters, making it impossible to draw any kind of robust conclusions overall.

Much of the evidence regarding clinical effectiveness and health service use shows no statistically significant differences between groups, suggesting that care closer to home interventions are no less effective than routine care. This is particularly the case for home care for mental health problems, technological care at home, and early discharge schemes. Quality of life outcomes were not considered across all interventions; however, when measured, a small amount of evidence was favourable towards care closer to home interventions. However, these findings must be considered in relation to the quality of the study designs, and thus the quality and credibility of the evidence.

Many of the studies included in this chapter employed weak designs and thus can be considered weak evaluations. Descriptions of methods often lacked transparency, making it difficult to establish the robustness of the designs. In the few studies where a control group was used for comparison, other methodological limitations lessened the credibility of the evidence.

5 Descriptive review

In addition to the included studies which evaluated models of care closer to home, we also reviewed papers which offered descriptive accounts of CCTH services which exist or have existed historically in the UK.[g] This chapter brings these accounts together to review the different types of service models that deliver some component of CCTH. Forty-five accounts of UK services (across 63 papers) were identified (see Chapter 2). The services identified can be broadly categorised into the following models:

- Generic home care
- Condition specific home care
- Children's Community Nursing (CCN) Teams
- Ambulatory Care
- Community based treatment for mental health problems
- Early discharge
- Palliative and hospice care
- Multiple integrated services.

It is important to note that these categories are not exclusive and that some overlap between service types is evident. For example, a CCN team may be based in the community and provide both hospital and community based care (e.g. at outpatient units, in schools) whilst also providing care within the child's home. Similarly, there may be overlap between condition specific home care, community based care and palliative care models (e.g. a home care team that provides palliative care). In analysing these descriptive accounts, therefore, we have grouped services into four broader categories: generic home care, condition specific home care, community-based care, including ambulatory care, and palliative and hospice care at home. Table 48 provides a summary of the types of care closer to home services within each of the four categories, and the papers which described them. As in previous chapters, we refer to studies by the first author and date of the main publication. Full bibliographical details are in Appendix 4.

[g] Literature that provided descriptions of care closer to home provision more generally (e.g. surveys of CCN provision), which did not relate to an existing or previously existing UK service, were not included.

Table 48. Included papers (descriptive accounts) of UK care closer to home services

Care closer to home model	Care closer to home service type	Included publications
Generic Home Care (5)	Home care for both acute and long term conditions	While (1991)
	Hospital at home for acute conditions	Davies and Dale (2003a, 2003b), Simmons (2003)
	Hospital at home for acute conditions	Sartain *et al.* (2001, 2002a, 2002b), Bagust *et al.* (2002)
	Hospital at home for acute conditions	Peter and Torr (1996)
	Home care for both acute and long term conditions	Coe and Gallagher (1999)
	Home care	Tatman *et al.* (1992)
	Hospital at Home	Jennings (1994)
Condition Specific Home Care (14)	Home care for diabetes	Lowes and Gregory (2004)
	Home care for diabetes	Schmitt (2006)
	Home care for diabetes	Kirk *et al.* (2003), Kirk and Thomas (2006), McEvilly and Kirk (2005), McEvilly (1998, 1996, 1991)
	Home care for buckle fractures of the distal radius	Symons *et al.* (2001)
	Home care for fractured femurs	Davies *et al.* (2001)
	Home traction	Orr *et al.* (1994
	Home traction	Clayton (1997)
	Home IV therapy	Hooker and Kohler (1999)
	Home oxygen therapy	Dunbar and Kotecha (2000)
	Home renal nursing	Gartland (1998), Cuttell (1996)

	Home parenteral nutrition	Holden *et al.* (1996)
	Home based wound care after injury or surgery	Teare (1997)
	Home care for soiling and constipation	Rennie *et al.* (1997)
	Telehome care for life limiting neurological impairments	Guest *et al.* (2005)
Community Based Care (18)	Emergency Assessment Unit	Aitken and Wiltshire (2005)
	Day case tonsillectomy	Shah *et al*. (2001)
	Paediatric Assessment Unit	Beverley *et al.* (1997)
	Emergency Assessment Unit	Coleman and Finlay (1997)
	Medical Day Unit	Smith *et al.* (1993)
	Ambulatory Care Unit	Cresswell (2002)
	Short Stay Unit	Beattie and Moir (1993)
Community Based Care (18) (continued)	Ambulatory Care Unit	Turner (1998)
	Community Intensive Therapy Team	Darwish *et al.* (2006)
	Ambulatory Paediatrics	Meates (1997)
	Children's Community Nursing Team	Coley and Partridge (2002)
	Children's Community Nursing Team	Hughes (1997)
	Children's Community Nursing Team	Linter *et al*. (2000)
	Children's Community Nursing Team	Walmsley and Moyse (2006)
	Children's Community Nursing Team	Dryden (1994)
	Children's Community Nursing Team	Wagner, cited in Martinson (1997)
	Short Stay Unit	Jackson (2000)
	Discharge planning/long stay house	Herouvin (2007), Gatford, (1999, cited in Smith, 1999)

Palliative and Hospice Care (8)	Symptom Care Team	Hunt (1991), Goldman *et al.* (1990)
	Hospice at home	Farrell and Allen (1998), Andrews and Hood (2003)
	East Anglia Children's Hospices	Maynard *et al.* (2005)
	Diana Princess of Wales Children's Community Team	Danvers *et al.* (2002), Beattie and Robson (2004)
	Avon Lifetime Service	Horrocks *et al.* (2002), Lewis (1999)
	Macmillan Paediatric Nursing Service	Kelly *et al.* (1996)
	Cornwall's Diana Community Nursing Team	Oliver (2000)
	CHASE Community Service	Menezes (2001)

5.1 Models of generic home care

These models refer to services that provide care within the child's home, and which are not limited to service provision for a particular condition. They may provide only generic acute care that would normally be addressed in acute inpatient units, or both generic acute care at home alongside home care for chronic and complex conditions. A total of seven descriptions of services (across 11 papers) providing generic home care in the UK were identified from our searches (Table 49). The most common element of the service models for generic home care was their purpose and aim. Six of the seven services in this respect stressed the importance of avoiding hospital admission by caring for the child in their home environment.

Table 49. Types of care closer to home (Generic Home Care)

Study	Service	Aim of service	Primary setting	Date service was established
While (1991)	Home Care Scheme	To provide care at home	Home	1988
Davies (2003a)	Hospital at Home	To care for children at home	Home	2000
Sartain (2002a)	Hospital at Home	To care for acute illness at home	Home	-
Peter (1996)	Hospital at Home	To provide an alternative hospital admission and hospital stay	Home	-
Coe (1999)	Home Care Team	To nurse children in their usual environments	Home	1987
Tatman (1992)	Home Care	To be an alternative to hospital admission for sick children being referred by general practitioners, casualty and outpatient departments; to shorten stay in hospital for admitted children; to support the families of children admitted to hospital and increase their independence by enabling them to provide nursing care at home; to provide an equitable service, accessible to disadvantaged families and giving families	Home	1989
Jennings (1994)	Hospital at Home	-	Home	1991

5.1.1 Staffing

The papers describing the seven generic home care services did not provide a detailed account of the staffing within each service, however all services were staffed predominantly by nurses (Table 50). Three services employed registered sick children's nurses (RSCNs (Coe, 1999; Tatman, 1992; Jennings, 1994) and two described 'home care nurses', or 'hospital at home nurses' (Davies, 2003a, 2003b; Simmons, 2003; Peter, 1996). Two accounts did not describe the types of nurses employed (While, 1999; Sartain, 2001, 2002a, 2002b; Bagust, 2002).

In addition to nursing staff, medical consultants were used in two services, one being a paediatric consultant (Sartain, 2001, 2002a, 2002b; Bagust, 2002) and the other described as a hospital consultant (Peter, 1996). The HaH scheme described by Davies and colleagues also drew upon the services of the local GP. In one case, the lead clinical responsibility for the child fell with the consultant (Peter, 1996), while the HaH service described by Davies (2003a, 2003b) stated that lead responsibility for the child was either with the GP or the home care nurse. For the other three home care services, this information was not stated.

Table 50. Staffing for generic home care services

Study	Nurses	Medical staff	GPs	Other	Staff with lead responsibility for child
While (1991)	Four full time nurses (three for home care, 1 based in hospital who provides cover when home nurses are unavailable)	-	-	-	
Davies (2003a)	One home care nurse	-	GP	-	GP or home care nurse
Sartain (2002a)	Nurses (number and grade not specified)	Paediatric consultant	-	-	-
Peter (1996)	Hospital at home nurse	Hospital consultant	-	-	Hospital consultant
Coe (1999)	5.8 WTE G Grade RSCNs	-	-	-	-
Tatman (1992)	Four full time RSCNs	-	-	1 full time Bengali interpreter, 1 part time secretary	-
Jennings (1994)	Five RSCNs, three nurses not otherwise specified				-

5.1.2 Service provision

All seven generic home care services delivered acute care provision, such as treatment for pyrexia, chest infections, diarrhoea, and gastro-enteritis, and dressings. In addition to general acute care, some services also provided complex care and care for chronic conditions such as asthma (While, 1999; Coe, 1999; Tatman, 1992). In addition to the clinical provision of care, most of the services also provided advice or support, suggesting that educating and empowering carers was a significant component of the service. Table 51 summarises this information.

Table 51. Nursing/ clinical activities offered within service (Generic Home Care)

Study	Number of activities reported	Type of activities reported
While (1991)	14	Advice & support, bowel care, bladder care, continuous oxygen care, discharge, dressings and wound care, drug administration, feeding, home visits, nutritional advice, physiological measurements, suture removal, teaching, terminal care.
Davies (2003a)	6	Observation and assessment, wound care, information and advice, IV medication, nebulisers, enemas
Sartain (2002a)	2	Education, home visits
Peter (1996)	1	Home visits
Coe (1999)	9	Home visits, advice and support, education, care coordination, management of pre-term babies after discharge, dressings, routine blood samples, routine follow up care for oncology/haematology, ongoing management of asthma, school visits for oncology/haematology patients.
Tatman (1992)	14	Dressings, skin care, asthma (nebulisers), asthma (no nebulisers), other respiratory, drug administration, renal care, special needs, prematurity, oncology, haemaglobinopathy, apnoea monitoring, heart defect, other.
Jennings (1994)	5	Examination, nursing procedures, support, bringing supplies, teaching procedures.

Overall, three common characteristics relating to the organisation of generic home care services are evident. First, the purpose and aim of each of these services was to avoid admission of children to hospital, and to care for children in their home environments. Secondly, each service was predominantly staffed by nurses. Thirdly, all services catered for general acute conditions. There was, however, slight variability in the models

described above in that some, but not all services also provided complex care.

5.2 Models of condition-specific home care

These models refer to services provided primarily in the child's home, but which are limited to care for one condition or a medical speciality. As a result, the care provided is specialist, which is reflected in the nature of the staff and the secondary settings of care, which are often hospital based. Fourteen services (across 20 papers) that provided home care for specific conditions or groups of children in the UK were identified (see Tables 52–56 for a summary of the characteristics of these services). Many, though, not all, of the condition specific home care services described in the literature differed from generic home care in that their ethos was often orientated towards *management of* the condition.

The 14 services identified were further sub-categorised into the following condition specific services: *diabetes* (three services), *technological* (four services), *orthopaedics* (four services), *renal* (one service), *wound care* (one service) and *soiling and constipation* (one service).

The aims of the services in this category varied depending on the condition of the child. For example, diabetic home care services (e.g. Lowes, 2004; Schmitt, 2006; Kirk, 2006) aimed to manage diabetes at home after diagnosis and reduce inpatient days. This aim was also reported for two of the orthopaedic services (Symons, 2001; Orr, 1994), while the third orthopaedic service aimed to nurse children with fractured femurs at home (Davies, 2001).

Table 52. Types of care closer to home (Condition Specific Home Care: Diabetes)

Study	Service	Aim of service	Primary setting	Date service was established
Lowes (2004)	Home management of diabetes	To manage diabetes at home		
Schmitt (2006)	Home management of diabetes	To manage diabetes at home (post diagnosis)		
Kirk (2006)	Diabetes Home Care Service	To manage diabetes at home and reduce inpatient bed days; to reduce separation and stress of admission to hospital		

Table 53. Types of care closer to home (Condition Specific Home Care: Technological)

Study	Service	Aim of service	Primary setting	Date service was established
Hooker (1999)	Home IV Therapy	To deliver IV therapy at home	Home	Not stated
Holden (1996)	Home parenteral nutrition	Not stated	Home	Not stated
Dunbar (2000)	Home oxygen therapy	To prevent hospital admission; to establish and nurture rapport with family and child; to educate parents/carers to manage their child with oxygen and equipment; to ensure discharge of child into safe home environment; to ensure smooth transition from hospital to home; to regularly assess and evaluate child's respiratory condition at home; to promote good nutritional status in child; to review and follow up child in community and hospital; to provide psychological support for family; to ensure adequate access to secondary care when needed; to review and remedy child's developmental progress.	Home	Not stated
Guest (2005)	Telemedicine for children with neurological impairments	To provide a tele-link between the child's home and hospital to give advice, in order to prevent the child coming into hospital for such advice	Home	Not stated

Table 54. Types of care closer to home (Condition Specific Home Care: Orthopaedics)

Study	Service	Aim of service	Primary setting	Date service was established
Symons (2001)	Home management of buckle fractures of the distal radius	To management fractures at home	Home	-
Orr (1994)	Home traction	To manage fractures and traction at home	Home	-
Davies (2001)	Home care for fractured femurs	To nurse children with fractured femurs at home	Home	1994
Clayton (1997)	Home traction	To offer home traction to a number of families; to avoid the home environment becoming a 'mini hospital'.	Home	-

Table 55. Types of care closer to home (Condition Specific Home Care: Renal)

Study	Service	Aim of service	Primary setting	Date service was established
Cuttell (1996)	Home renal nursing service	To provide renal nursing care at home	Home	1985

Table 56. Types of care closer to home (Condition Specific Home Care: Other)

Study	Service	Aim of service	Primary setting	Date service was established
Teare (1997)	Home care for wound care after injury or surgery	To enable early discharge and prevent admission	Home	Not stated
Rennie (1997)	Home care for soiling and constipation	To minimise inpatient stay; prevent admission; reduce outpatient visits; and promote independence by handing care over to the family	Home	Not stated

For technological services such as home parenteral nutrition and home IV therapy, the aim was solely to deliver the service at home, rather than in hospital. For home oxygen therapy, many aims were reported, and included preventing hospital admission, to educate parents and children to manage oxygen equipment and also to support the family in transition of the child to home. Prevention of hospital admission was also reported as an aim for the home care team for soiling and constipation (Rennie, 1997) and the telemedicine service (Guest, 2005).

From this it is clear that the nature of the care was, overall, more long term, as opposed to the shorter term care that was seen in generic models of care.

5.2.1 Staffing

As with the staffing of generic home care services, condition specific services were staffed predominantly by nurses. Reflecting the condition specific nature of the services, such nurses were often specialists in the condition catered for. The staffing in these services, however, differed from generic home care services in that the teams were larger and more multidisciplinary (see Tables 57–61). For example, the diabetic home care team reported by Kirk (2006) employed a paediatric diabetes specialist nurse, a consultant paediatrician, and a diabetes home care co-ordinator, as well as allied health staff such as dieticians.

Table 57. Staffing for condition specific home care services (Diabetes)

Study	Nurses	Medical staff	GPs	Allied Health Professional	Other
Lowes (2004)	Paediatric diabetes specialist nurse	Not stated	Not stated	Not stated	None stated
Schmitt (2006)	Paediatric diabetes specialist nurse, 4 diabetes link nurses based at hospital to provide cover for the specialist nurse	Paediatric consultant	Not stated	Not stated	None stated
Kirk (2006)	Diabetes specialist nurse	Paediatric consultant	Not stated	Dieticians (number not specified)	Home care co-ordinator, administrative staff

Staff with lead responsibility for child was not stated in any of these studies.

Table 58. Staffing for condition specific home care services (Technological)

Study	Nurses	Medical staff	GPs	Allied Health Professional	Other	Staff with lead responsibility for child
Hooker (1999)	Unspecified number of community nurses	Not stated	Not stated	Not stated	None stated	
Holden (1996)	3 nutritional care sisters	Two gastroenterology consultants	Not stated	Dietician, specialist pharmacist	Clinical chemist, social worker	
Dunbar (2000)	Respiratory nurse specialist	Hospital paediatrician, community paediatrician	GP	Dietician, health visitor, physiotherapist, speech therapist, occupational therapist, educational psychologist	Social worker	
Guest (2005)	Specialist neurology nurse, neurology support nurse	Consultant	Not stated	Not stated	None stated	Not stated

Table 59. Staffing for condition specific home care services (Orthopaedics)

Study	Nurses	Medical staff	GPs	Allied Health Professional	Other	Staff with lead responsibility for child
Symons (2001)	Nursing staff (not otherwise specified)	Not stated	Not stated	Not stated	None stated	Not stated
Orr (1994)	District nurse	Orthopaedic consultant	Not stated	Not stated	None stated	Not stated
Davies (2001)	Orthopaedic nurse specialist	Hospital orthopaedic consultant	GP	Not stated	Unspecified community support staff, hospital teacher	Hospital orthopaedic consultant
Clayton (1997)	Children's community nurses	Ward staff (not otherwise described)	None stated	None stated	None stated	Not stated

Table 60. Staffing for condition specific home care services (Renal)

Study	Nurses	Medical staff	GPs	Allied Health Professional	Other	Staff with lead responsibility for child
Cuttell (1996)	Paediatric renal nurse, Community paediatric renal nurse, renal on-call nurse	Not stated	GP	Not stated	Unspecified multi-disciplinary team	Community Paediatric Renal Nurse

Table 61. Staffing for condition specific home care services (Other)

Study	Nurses	Medical staff	GPs	Allied Health Professional	Other	Staff with lead responsibility for child
Teare (1997)	Four paediatric nurses, unspecified number of community nurses	Not stated	Not stated	Not stated	Not stated	Not stated
Rennie (1997)	Five nursing sisters	Not stated	Not stated	Not stated	Not stated	Not stated

In the home renal nursing service described by Cuttell (1996) and Gartland (1998), an unspecified multidisciplinary team was used alongside a specialist renal nurse, a community nurse and a home care nurse. Perhaps the most multidisciplinary team among the condition specific services was that described by Dunbar (2000) in relation to the home oxygen therapy service. Here, the staff consisted of a hospital paediatrician, a respiratory nurse specialist, a dietician, the family doctor, a health visitor, a community paediatrician, a physiotherapist, a speech therapist, an occupational therapist, an educational psychologist and a social worker.

Although specialist nursing staff comprised the core component of the staffing for these services, most did not state with whom lead responsibility for the child fell. The home renal service described by Cuttell (1996) stated that the community paediatric renal nurse held the lead clinical responsibility, while hospital orthopaedic consultants assumed lead responsibility within the home care team for fractured femurs (Davies, 2001).

5.2.2 Service provision

The care provision for these types of services tended to reflect the condition, as one would expect. For example, the care provision of diabetes home care teams seemed to centre on management through education and support, with some clinical care (such as injections). For the orthopaedic services, service provision mainly addressed the management of the dressing, such as removal of a backslab at home. This was also the case for the wound care team described by Teare (1997).

Among the technological services, provision mostly centred on the technology itself and appeared not to extend beyond associated clinical care and management. The telemedicine service offered advice and support (Guest, 2005), as did the soiling and constipation nursing service, in addition to bowel and bladder care (Rennie, 1997). The home renal nursing service offered activities such as dressings, drug administration, education,

feeding, general nursing and advice and support (Cuttell, 1996; Gartland, 1998). Tables 62–65 summarise this information.

Table 62. Nursing/ clinical activities offered within service (Condition Specific Home Care: Diabetes)

Study	Number of activities reported	Type of activities reported
Lowes (2004)	3	Home visits, support, education
Schmitt (2006)	2	Home visits, education
Kirk (2006)	4	Routine home and emergency visits, education, support injections

Table 63. Nursing/ clinical activities offered within service (Condition Specific Home Care: Technological)

Study	Number of activities reported	Type of activities reported
Hooker (1999)		stration
Holden (1996)		anning, education, training families, home visits
Dunbar (2000)		oxygen therapy
Guest (2005)		s via tele-link

Table 64. Nursing/ clinical activities offered within service (Condition Specific Home Care: Renal)

Study	Number of activities reported	Type of activities reported
Cuttell (1996)	7	Advice and support, home visits, administering medications and dietary supplements, dressings, overnight dialysis, setting up equipment, overnight feeding.

Table 65. Nursing/ clinical activities offered within service (Condition Specific Home Care: Orthopaedics)

Study	Number of activities reported	Type of activities reported
Symons (2001)	1	Removal of backslab at home by parents with final follow-up at out-patient clinic
Orr (1994)	2	Home visits, home traction
Davies (2001)	2	Home visits, home traction
Clayton (1997)	2	Home visits, home traction

Although each of the condition specific services identified in the literature varied considerably due to the focused nature of the care, three common aspects were apparent. Firstly, the purpose of the condition specific home care services was to manage the condition at home, where the service that would normally be provided in the hospital had been transferred to the child's home. This was particularly the case with the diabetic home care teams, the orthopaedic home care teams and services such as home oxygen therapy and HPN. Most services also reported the objective of preventing admission and reducing inpatient days, which collectively shows a common aim of minimising and replacing hospital based care.

Secondly, although the staff teams differed depending on the condition being cared for, collectively, staff teams in most cases were specialist, employed a number of nurses, and were of a multidisciplinary nature. This contrasts with the staffing seen in generic home care and shows that staffing models can be conceptualised as predominantly nurse-led versus multidisciplinary. Lastly, and as expected, service provision was focused on management and clinical care specifically relating to the condition in question, as opposed to the more generic provision seen in generic home care.

5.3 Models of CCN teams

Models of CCN teams have been distinguished from home care teams in this review simply because this distinction is apparent in the literature. As shown below, however, these services appear to be similar to one another, although much less information about CCN teams was available in these accounts. The difference in 'title' may be superficial, and merely a result of how care closer to home has evolved in practice. A total of six accounts of CCN teams in the UK were identified in our review, and are summarised in Table 66. As with models of generic and condition specific home care, the overall purpose of these services was to keep ill children and young people

out of hospital, either by preventing admission, reducing length of stay or facilitating early discharge. In one service, an additional aim of improving ties between acute and primary care was also reported (Wagner, 1997).

Table 66. Types of care closer to home (Community Based Care: Children's Community Nursing Team)

Study	Service	Aim of service	Primary setting	Date service was established
Coley (2002)	Children's Community Nursing Team	Reduce admission and length of stay; promote family/child satisfaction with service	Community/home	Not stated
Walmsley (2006)	Children's Community Nursing Team	To care for children with a minor injury or acute illness and support family to nurse child in the home, as opposed to being admitted to hospital	Not stated	Not stated
Wagner (1997)	Community Paediatric Nursing Team	To prevent hospital admission; to reduce admission rates; to increase the number of day cases; to reduce the length of stay from 2.92 days to 2 days; to improve collaboration between acute, community and primary care services	Not stated	1995/1996
Hughes (1997)	Children's Community Nursing Team	To promote earlier discharge and prevent ward attenders	Community	1990
Linter (2000)	Children's Community Nursing Team	To provide nursing care for children with chronic and complex needs after discharge	Community/home	Not stated
Dryden (1994)	Children's Community Nursing Team	Not stated	Not stated	1984

5.3.1 Staff

Similar to models of home care, the services were staffed predominantly by nurses. Where the staffing models for CCN teams tended to differ from that

of home care teams, was in the apparently wide skill mix among the nurses, with a number of different nursing specialisms reported (e.g. Dryden, 1994, Coley, 2002). In addition to nurses, staff from general practice, as well as pharmacists (Wagner, 1997), home support carers (Linter, 2000) and a play therapist (Coley, 2002) were also reported. Table 67 summarises this information.

Table 67. Staffing for community based services (Children's Community Nursing Teams)

Study	Nurses	Medical staff	GPs	Allied Health Professional	Other	Staff with lead responsibility for child
Coley (2002)	1.0 WTE G grade nurse, 3.24 WTE F grade nurses, 0.8 WTE G grade children's	Not stated	Not stated	Play specialist	None stated	Not stated
Walmsley (2006)	Unspecified number of children's community	Not stated	Not stated	Not stated	None stated	Not stated
Wagner (1997)	7.9 WTE paediatric & general nurses	Hospital consultant	GP	Not stated	Local pharmacists	Hospital consultant
Hughes (1997)	5.3 WTE Nurses	Not stated	Not stated	Not stated	None stated	Not stated
Linter (2000)	Three children's nurses	Not stated	Not stated	Not stated	Home support carers	Not stated
Dryden (1994)	Five community nurses, 2 specialist diabetes nurses, 2 family therapy nurses, 1 asthma nurse, children's renal community nurse, senior sister H grade	Not stated	Not stated	Not stated	None stated	Not stated

5.3.2 Service provision

Although few of the services identified reported whether they were hospital based providing outreach, or community based providing in-reach, it can be assumed that the primary setting of care was the child's home, although Linter (2000) also noted the school as a setting. For some of the services identified (e.g. Linter *et al.*, 2000; Hughes, 1997; Coley, 2002) a wide range of care provision was reported (see Table 68).

Table 68. Nursing/ clinical activities offered within service (Community Based Services: Children's Community Nursing Teams)

Study	Number of activities reported	Type of activities reported
Coley (2002)	5	Day surgery follow up, home traction, tracheostomies, administering of eye drops, home visits
Walmsley (2006)	1	Home visits
Wagner (1997)	-	-
Hughes (1997)	8	Dressings, follow up observations, support visits, follow up oxygen therapy, administration of IV drugs, terminal care, eczema care, enema care
Linter (2000)	5	Advice and support, assessment, education, hands on care, selection purchase and maintenance of equipment
Dryden (1994)	2	Palliative support, dressings.

Overall, CCN teams are similar in many ways to models of home care (either generic or specialist). Where they do differ, this seems to related to a wider skill mix.

5.4 Models of ambulatory care

Our study defines care closer to home by its functions of preventing admission to hospital and reducing length of stay, as well as the location of care.[h] Such functions can be met through services that aim to 're-route' referrals to hospital (for example, through a GP or A&E) and filter those that require an admission and those that do not. Such services include short stay wards and day assessment units – more generally known as ambulatory units. Such units specifically for children and young people are becoming increasingly common, as findings from our national survey of care closer to home demonstrated (Parker *et al.*, 2010). This category is about

[h] For further commentary on this, the reader is referred to the main project report.

these types of services, and in addition a day case surgery service, which has been included in this category due to its aim of reducing unplanned hospital admission.

A total of ten services (across ten papers) were identified for this category, and are summarised in Table 69. As stated above, the general aim of such services is to prevent admission to hospital, and this was the stated aim for four services reported here (Aitken, 2005; Shah, 2001; Coleman, 1997; Meates, 1997). One service aimed to enable early discharge for children with acute conditions (Jackson, 2000), and one aimed to provide assessment of emergency referrals (Smith, 1993). Three descriptions did not state the aims of the service.

Table 69. Types of care closer to home (Community Based Care: Day Units/ Assessment Units/ Short Stay Units)

Study	Service	Aim of service	Primary setting	Date service was established
Aitken (2005)	Emergency Assessment Unit	To provide emergency assessment without the need for admission to hospital	Emergency Assessment Unit	1998
Shah (2001)	Day case tonsillectomy and following home care	To reduce unplanned hospital admission	Not stated for day case tonsillectomy, but at home for following home care	Not stated
Jackson (2000)	Short Stay Unit	To enable early discharge for children with acute conditions	Hospital	1998
Beverley (1997)	Paediatric Day Assessment Unit	Not stated	Day unit	1995
Coleman (1997)	Emergency Assessment Unit	To reduce inappropriate admissions to hospital	Assessment unit	Not stated
Meates (1997)	Ambulatory Paediatrics	To prevent hospital admission and provide care in child's home	Community (not otherwise specified)	Not stated
Smith (1993)	Medical Day Unit	To provide a service for programmed investigations, day case treatment, assessment of	Day unit	1981

		emergency referrals		
Cresswell (2002) Service 3[a.]	Ambulatory Care Unit	-	Ambulatory unit on hospital site	2001
Beattie (1993)	Short stay unit	-	Hospital	1990
Turner (1998)	Ambulatory Care Unit (Non-Surgical)	-	-	-

a. Of three services described, one fell into this category of CCTH

5.4.1 Staff

While the previous service models reported a predominantly nursing staff, ambulatory models reported both nurses and doctors of various levels of training and specialism (see Table 70). Nurses were reported by seven services (Aitken, 2005; Jackson, 2000; Beverley, 1997; Coleman, 1997; Meates, 1997; Smith, 1993; Cresswell, 2002), while consultants were reported by two services (Shah, 2001; Beverley, 1997), paediatric consultants by two (Coleman, 1997; Cresswell, 2002), other paediatricians by four (Coleman, 1997; Meates, 1997; Smith, 1993; Cresswell, 2002), and other doctors (e.g. associate specialists, surgeons, SHOs, registrars) by four (Shah, 2001; Beverley, 1997; Smith, 1993; Cresswell, 2002).

Table 70. Staffing for community based services (Day Units/ Assessment Units/ Short Stay Units)

Study	Nurses	Medical staff	GPs	Allied Health Professional	Other
Aitken (2005)	Nurses (number and type not specified)	Not stated	Not stated	Not stated	None stated
		ENT doctor, unspecified number of consultants, associate specialists and staff grade surgeons			
Jackson (2000)	Unspecified children's nurses and community nurses, school & practice nurse	Not stated	GP	Health visitor	None stated

Beverley (1997)	4.5 WTE nurses	Consultant on-call, Senior House Officer, middle grade doctor	Not stated	Not stated	None stated
Coleman (1997)	1 nurse	Consultant paediatrician, paediatric middle grade staff	Not stated	Not stated	None stated
Meates (1997)	6 G grade nurses	Ambulatory paediatrician	Not stated	Not stated	None stated
Smith (1993)	4 full time nurses, 2 part time nurses	Paediatric registrar	Not stated	Not stated	None stated
Cresswell (2002) Service 3	10.4 WTE nurses (RSCN or equivalent)	Consultant paediatrics, 1 WTE specialist registrar, 1 WTE staff grade (paediatrics)	1 WTE GP registrar	0.2 WTE physiotherapist, speech therapist, dietician, 0.8 WTE play leader support.	-

Staff with lead responsibility for child was not stated in any of these studies.

The Beattie (1993) and Turner (1998) descriptions gave no details of staffing.

These accounts suggest that ambulatory models are staffed more by medical doctors rather than nurses – a clear contrast to the staffing models associated with home care and CCN teams. A possible explanation of the dominance of medical doctors in this model is the way such units are managed. Ambulatory care units are often conjunct to paediatric inpatient wards and can 'share' the inpatient nursing staff (see survey findings). Such services may operate under the medical supervision of a named or dedicated medical doctor, and may not be formally staffed by nurses, but may instead have nurses attached to the unit who provide care when necessary.

5.4.2 Service provision

As the purpose of ambulatory services is to prevent admission to hospital, service provision will include assessments, investigations and day treatment or surgery (Aitken, 2005; Meates, 1997; Smith, 1993; Coleman, 1997; Shah, 2001). In addition to this, three services also provided following up either through home visits (Shah, 2001) or via telephone (Jackson, 2000; Meates, 1997). Table 71 summarises this information. As provision is focused around acute needs, the nature of the care is likely to be short term.

Table 71. Nursing/ clinical activity offered within service (Community Based Care: Assessment Units/ Day Units/ Short Stay Units)

Study	Number of activities reported	Type of activities reported
Aitken (2005)	1	Emergency assessment
Shah (2001)	1	Home visits after day case surgery
Jackson (2000)	2	Liaison with other professionals, follow up telephone calls
Beverley (1997)	-	-
Coleman (1997)	4	Radiography investigation, microscopy investigation, blood tests, EEG
Meates (1997)	4	Home visits, telephone follow up, assessment and investigations.
Smith (1993)	3	Programmed investigations, day case treatment, assessment of emergency referrals.
Cresswell (2002) Service 3	-	-
Beattie (1993)	-	-
Turner (1998)	-	-

Overall, while generic home care, condition specific home care and CCN teams appear to share certain characteristics and perhaps have similar service models, ambulatory care models are quite distinct due to the primary setting of care (hospital), the substantial involvement of medical staff, and the short term and very specific nature of the service provision. For this reason, ambulatory care is highly specific and thus discreet from other models of care closer to home.

5.5 Models of community based mental health for children and young people

Just one account of a UK service was identified in this part of the review. The paper described a community based team, although it was not clear what settings 'community' refered to (Darwish, 2006). This service aimed to manage children and young people with mental health problems referred from Tiers 2 and 3 services and prevent admission to hospital. The service staffing included a number of professions, including a psychiatrist, a psychologist, a staff grade doctor, three nurse therapists and two support

workers. Services included observation, medication treatment, therapies, investigations, dietetic support and psychological testing.

5.6 Models of early discharge for children who are technology dependent

One account of a service was identified in the literature which seemed quite distinct from others identified, in that it provided a 'step down' house for children dependent on technology after discharge, prior to going home (Herouvin, 2007; Gatford, cited in Smith, 1999). Unfortunately, little further information was available about this service, other than it was for technology dependent children and facilitated discharge.

5.7 Models of palliative and hospice care

Models of care closer to home in this category include care that is primarily palliative, which may be provided in the home or in the community, and care in hospices, which may also deliver care in the community and home. As a result, there was some overlap with the home care models and the community based care models. Owing to the highly specific nature of this type of care, however, these types of services are described in this separate category in order to highlight differences in the service models. Accounts of a total of eight services (in ten papers) providing palliative and hospice care were identified in the review. The service features of these are discussed further below and are summarised in Table 72.

Table 72. Types of care closer to home (Palliative Care)

Study	Service	Aim of service	Primary setting	Date service was established
Hunt (1991)	Symptom Care Team	To support families caring for children with cancer once they have been discharged into the community; to improve symptom management of terminally ill children.	Home	1986
Andrews (2003)	Hospice at Home	To provide direct nursing support for terminally ill children in their home	Home	1996
Maynard (2005)	East Anglia Children's Hospices	Not stated	Home/ Hospice	Not stated
Beattie (2004)	Diana, Princess of Wales Children's Community	To provide palliative care in the child's home and as an alternative to hospital admission; facilitate earlier	Home	Not stated

	Team	discharge from hospital; provide 24 hour terminal care.		
Horrocks (2002)	Avon Lifetime Service	To provide community and psychological services to children and families of children with life limiting illnesses.	Home	1998
Kelly (1996)	Macmillan Paediatric Nursing Service	To provide supportive and palliative care to children discharged from hospital at any stage of treatment or with any type of cancer	Home	1990
Oliver (2000)	Cornwall's Diana Community Nursing Team	Provide ongoing nursing care in the community and at home for children with life threatening and life limiting illnesses	Home	1998
Menezes (2001)	CHASE Community Service	To provide palliative care in the child's home	Home	1999

5.7.1 Types and location of service

Three hospice services were identified that provided care primarily at home and secondarily within the hospice. These included the Hospice at Home service at Derian House, (Farrell, 1998; Andrews, 2003); the East Anglia Children's Hospice (EACH) service (Maynard, 2005); and the CHASE community service provided by the CHASE hospice in Kent (Menezes, 2001). Five services were identified that provided care primarily at home, which included the Symptom Care Team (Hunt, 1991; Goldman, 1990), two Diana Community Children's Teams (Danvers, 2002; Beattie, 2004; Oliver, 2000), the Avon Lifetime Service (Horrocks, 2002; Lewis, 1999) and the Macmillan Paediatric Nursing Service (Kelly, 1996).

5.7.2 Purpose

All services, except EACH (which did not report an aim or purpose) reported an aim of providing nursing and palliative care and support to children and families. In most services, this was particularly the aim for children with life limiting illnesses. One of the Diana Community Teams aimed to provide care in the child's home as an alternative to hospital admission, and also to facilitate earlier discharge from hospital (Danvers, 2002; Beattie, 2004).

5.7.3 Staffing

Most of the services (seven out of eight) were staffed by nurses (one service did not report staffing), who were clinical specialists (Hunt, 1991; Goldman, 1990), children's community nurses (Danvers, 2002; Beattie, 2004; Horrocks, 2002; Lewis, 1999), children's nurses (Oliver, 2000; Menezes, 2001) or Macmillan nurses (Kelly, 1996). Services also included doctors (Hunt, 1991; Goldman, 1990; Horrocks, 2002; Lewis, 1999), psychologists (Danvers, 2002; Beattie, 2004; Horrocks, 2002; Lewis, 1999; Oliver, 2000), allied health therapists, such physiotherapists and occupational therapists, as well as art and play therapists (Menezes, 2001; Oliver, 2000; Danvers, 2002; Beattie, 2004) and administrative support (Hunt, 1991; Goldman, 1990; Menezes, 2001). In one Diana service there was a cultural link worker (Danvers, 2002; Beattie, 2004) and in the CHASE community service, a social worker was also involved (Menezes, 2001). Table 73 summarises this information.

Table 73. Staffing for palliative care services

First author and date	Nurses	Medical staff	GPs	Allied Health Professional	Other	Staff with lead responsibility for child
Hunt (1991)	Three clinical nurse specialists	1 doctor (grade not specified)	Not stated	Not stated	Lecturer in Palliative Care, secretary	Not stated
Andrews (2003)	Not stated	Not stated	Not stated	Not stated	Not stated	Not stated
Maynard (2005)	'Nurse led'	Not stated	Not stated	Not stated	Not stated	Not stated
Beattie (2004)	Unspecified number of respite, oncology and children's community nurses	Not stated	Not stated	Clinical Psychologist, Occupational therapist, PhysiotherapistPlay specialist	Service manager, cultural link worker, residential respite team, support staff	Not stated
Horrocks (2002)	Three paediatric community nurses, unspecified number of senior nurse managers	Unspecified number of hospital based consultants	Not stated	Two part time child psychologists	Not stated	Not stated
Kelly (1996)	Unspecified number of	Not stated	Not state	Not stated	Not stated	Not stated

	Macmillan nurses with support from community and district nurses		d			
Oliver (2000)	Two children's nurses	Not stated	Not stated	One part time clinical psychologist, 1 part time art therapist, 1 physio/ occupational therapist	Eight support workers	Not stated
Menezes (2001)	One Lead nurse, 2 children's nurses	Not stated	Not stated	One health visitor	Four team leaders, 1 director of care, 1 part time administrator	Not stated

5.7.4 Service provision

All services catered for children with palliative care needs, however five also offered generic service provision (Farrell, 1998; Andrews, 2003; Danvers, 2002; Beattie, 2004; Horrocks, 2002; Lewis, 1999; Oliver, 2000; Menezes, 2001). Two services were condition specific. These were the Symptom Care Team, and the Macmillan Paediatric Nursing Service, both of which provided care for children with cancer. Models of palliative care can thus be separated into generic and condition specific, much like the other models of home care.

All services offered advice and support, and three services offered a wide range of activities (see Table 74). The Symptom Care Team, the Macmillan Paediatric Nursing Service and the Leicestershire Diana Community Team offered a mix of activities such as general nursing care, general palliative care, education, social support, feeding, dressing and bowel and bladder care. In addition to these, the Leicestershire Diana Community Team offered play therapy, language interpretation support, phlebotomy, counselling, physiotherapy and massage. The Derian House Hospice at Home and the EACH service both offered palliative care not otherwise specified, whilst care activities were not reported for five of the services (Horrocks, 2002; Lewis, 1999; Oliver, 2000; Menezes, 2001).

Table 74. Nursing/ clinical activity offered within service (Palliative Care)

First author and date of main publication	Number of activities reported	Type of activities reported
Hunt (1991)	4	Management of physical symptoms, psychosocial support and liaison within the community, drug administration
Andrews (2003)	2	Teaching, support
Maynard (2005)	-	-
Beattie (2004)	-	-
Horrocks (2002)	-	-
Kelly (1996)	4	Providing information, support, nursing care, symptom control
Oliver (2000)	-	-
Menezes (2001)	-	-

While the focus of care can clearly set apart these palliative care services into a discreet model, certain components, such as staffing, overlap with other models. The two dimensions of service provision (generic versus condition specific) and the home care setting also suggest that, conceptually, such services might be better placed in a typology under a model of home care.

5.8 Multiple integrated service models

In addition to the services identified and categorised above, a number of other descriptive accounts of broader services structures were identified – these were predominantly in a report by Cresswell (2002) and also Meates (1997). The Cresswell report detailed accounts of eight areas (NHS trusts) where multiple health services for children worked in an integrated way. These services where possible have been allocated to the categories above, however to describe the wider service context of each here would provide little value and the reader is referred to the original publication. Some of the services described in the Cresswell report are the same services as found in other papers and thus have been reported alongside the other accounts in this chapter.

The Meates paper, while describing an ambulatory care unit in some detail, set the service within the wider context of paediatric health services and again, it has been too difficult to tease apart all of these services for this review. These multiple integrated services however have been

acknowledged here as they do describe broader models of children's health care, which in some cases include CCTH services.

5.9 Discussion and conclusions

The substantial variation in service provision for care closer to home revealed in these descriptive accounts indicates that there are three 'dimensions' to how UK care closer to home services can be conceptualised. Firstly, models can be distinguished as being primarily home based or hospital based. Secondly, services can be either generic or condition specific. The nature of the staffing appears to be reflected in this distinction. Thirdly, care can be short term or long term (dictated by whether the service provided acute care or not). The second and third dimensions relate primarily to models of home based care. Thus ambulatory models of care provided exclusively in hospital settings are much simpler and appear to vary little in terms of their service delivery and organisational characteristics.

The objectives of CCTH suggest that primary care will play a key role, particularly when that care is provided in the community. Very few of the accounts identified for this chapter, however, discussed the implications for primary care. Some, though, do describe the importance of cultivating relationships with and building ties into primary care (e.g. Simmons, 2003; Davies, 2003a; Coe, 1999). In some cases, there was an indication that primary care staff felt their workload might increase with the implementation of CCTH services (e.g. Davies, 2003; Peter, 1996). Other services also highlighted the involvement of the GP, but with little discussion of how this was done and to what effect.

Although these accounts offer some insight into CCTH services, information about all aspects of service delivery and organisational characteristics in which we were interested was not available in some cases, and thus a comprehensive understanding of this type of care is not possible. Given the variability in the services that provide CCTH for ill children and young people, comprehensive work is needed to explore patterns of service provision, and how services are organised and delivered. The national survey carried out as part of the main project (see Parker *et al.*, 2010) has started that process.

6 Studies including some element of health economics

As discussed in Chapter 2, as well as including RCTs and other comparative studies in the review, we also reviewed studies that had attempted some element of health economic evaluation of models of care closer to home. We were not interested, here, in studies that only calculated the costs of models of home care but in those that compared these costs with those of other, usually hospital-based, care. Some of the studies reviewed in this chapter were also reviewed in Chapters 3 to 5, as appropriate; some are entirely new.

The material is presented in sections, according to the ways in which the types or models of care being evaluated clustered together. This follows the approach adopted elsewhere in the report. Six main groups of studies were evident:

- Home care and supported early discharge for very low birth weight (VLBW) or medically fragile babies
- Home care for children with diabetes
- Home care for children with mental health problems
- Admission avoidance/early discharge for acute physical conditions
- Home chemotherapy and home care for complications
- Technological care at home, including nocturnal dialysis.

As in other parts of the report, for ease of reading studies are referred to by the name of the first author and data of publication. Full publication details of the papers are in Appendix 5.

6.1 Home care and supported hospital discharge for very low birth weight or medically fragile babies

Two different types of studies were included in this section. First, there were two studies of services developed specifically to provide home-based nursing and support for babies being discharged from neonatal intensive care units (NICUs) and their families. Secondly, there were two studies of medically fragile babies returning home with a specific form of technological support (gavage feeding; supplemental oxygen) where there was no specifically designed package of home care but families received some form of support through the initial period after discharge. We review these two types of studies separately.

6.1.1 Home-based nursing and support packages for babies being discharged from NICUs

Types of study

Two cost effectiveness studies were included in this category.

Swanson (1997) examined costs and outcomes for babies requiring naso-gastric feeding or oxygen, managed under the Neonatal Integrated Home Care Programme (NIHCP), compared to those managed in hospital. During the study year (1996), the home care team followed 20 of all 567 NICU discharges.

Spinner (1998) compared costs and outcomes for infants on an early discharge programme from intensive care nurseries in five participating hospitals. Ninety-three eligible babies were admitted to the intensive care nurseries during the study period, July-September 1995, 43 of whom required home care in order to be discharged. All these were included in the study.

Nature of intervention

Swanson (1997) reports on the NIHCP, which was developed to cross-train NICU nurses to provide follow-up care at home for high-risk neonates. Initial target populations were premature infants in transition to oral feeds and oxygen-dependent neonates, but this was extended to cover a wide range of medical conditions and nursing care needs. The staff from the NICU were trained in home care approaches and provided 'outreach' from the NICU; hours available to home-based care were thus influenced by demands within the NICU. It is not entirely clear from the published paper exactly what service input the outreach nurses provided, but there is reference to monitoring, liaising with hospital-based staff to implement changes in treatment regime and support for parents providing technological care for their babies.

Spinner (1998) reported on a multidisciplinary approach to early discharge of infants from NICUs. The prospectively designed programmes included case management, and at home infants received a combination of home oxygen, monitoring, intravenous antibiotics, gavage feedings, phototherapy or nutritional management. Home care nurses were available 24-hours a day and monitored the babies' progress, provided help with feeding and IV antibiotics, and supported the family.

Cost data collected

Table 75 summarises the cost data collected for the two studies.

Swanson (1997) utilised two average costs: the daily NICU cost and the home care cost per case. These are not broken down to their component parts. Reduction in length of stay and readmission rates are also reported, but there are neither baseline data nor data following the implementation of the outreach service.

Spinner (1998) used a previously devised 'days saved measure' which was designed to calculate and document hospital days saved by the comprehensive home care services. The tool involved four elements: acuity assigned to the baby, anxiety level of the carer, complexity of the baby's care needs, and level of technological support required. A score of one, two

or three was given for minimal, moderate or severe, respectively, in each element, and then totalled for each baby. The threshold for saving a day of care was set at a total score of six. Costs included hospitalisation and rehospitalisation, home care visits, emergency room visits, acute care visits, overhead and administrative costs and the salary of the nurse coordinator. All costs were determined by the insurer as the amount of money that would have been paid for the service. Daily savings were calculated according to the type of unit the baby was assumed to have required if they had remained in hospital.

Table 75. Type of cost data collected

Data collected	Swanson (1997)	Spinner (1998)
Hospital in-patient care per day	Yes	Yes
Hospital stay	Yes	-
Home care/case	Yes	-

Reported costs of care

Table 76 summarises average costs under the different models of care.

Table 76. Reported average costs

	Swanson (1997)	Spinner (1998)
Hospital in-patient care per day	US$1,200	US$7,674
Home care/case	US$940	-

Swanson (1997) applied costs of US$1,200 per day for the NICU and US$940 per case for babies managed at home. The calculated savings for the two original target populations as shown in Table 77 use cost data rather than reimbursement or charge data. Savings attributable to the reduction in readmission rates were not included.

Table 77. Average savings reported (Swanson, 1997)

Target population	Outcome	Method for calculation of cost savings per case	Total and average cost savings
Naso-gastric feeding transition for stable preterm infants	Decrease in LOS by 9.3 days from birth weight average	9.3 days @ daily NICU cost less cost of home care case	For 11 cases: Total savings: $112,420 Average savings: $10,220
Oxygen -dependent neonates	Decrease in LOS by 42 days from previous practice	42 days @daily NICU cost less cost of home care case	For 25 cases: Total costs: $1,236,500 Average savings: $49,460

All NICU discharges	9 readmission rate within 30 days reduced to 4.5 for all cases	Not calculated	N/A

Using the Days Saved Measure, Spinner (1998) estimated that home care for 43 infants saved 456 total hospital days, equating to an average of 10.6 days per infant. Based on reimbursed charges by the payer, the study calculated that $329,982 had been saved, an average of $7,674 per infant. The authors infer that they have taken account of additional costs of out-patient care and of the scheme, but no costs are provided in the published paper, merely the total savings.

Economic analysis

Swanson (1997) demonstrated savings associated with fewer in-patient days in a NICU. The average cost of home care was calculated to be US$940 per case. For infants requiring naso-gastric feeding an average of 9.3 days of NICU time was saved, equating to savings of US$10,220 per case (calculated by us). For oxygen dependent neonates, homecare reduced NICU stay by an average of 42 days, equating to a saving of US$49,460 per case (calculated by us). Readmission rates also fell from nine per cent to 4.5 per cent, although it is not entirely clear how this was calculated. No further outcomes were investigated although the authors stated that the parents were satisfied, and that nurses participating in the programme achieved improved professional development and work satisfaction.

Spinner (1998) shows that 83 per cent of parents were largely satisfied with the outcomes of and support received with home care. Early discharge with home care led to a decrease of 456 hospital days required, an average of 10.6 per baby. This equated to a hospital cost saving of US$329,982 in total for the programme, or US$7,674 per infant. Outcomes were similar for home care infants. Thus, despite the additional costs of establishing the home care service, significant savings were realised. The authors recognise that this was not a controlled study, and the number of babies was small. However, they do believe that length of hospitalisation could be routinely reduced using this model of care directed at discharge.

6.1.2 Supported hospital discharge for medically fragile babies

Type of study

Two studies were included in this section, the first (Sturm, 2005) adopted a cost effectiveness approach and the second (Greenhough, 2002) a cost utilisation approach.

Sturm (2005) undertook a retrospective review comparing costs and outcomes for pre-term babies receiving a home gavage-feeding programme to those receiving hospital care. During the 33-month period of the study, 143 infants met the physiological criteria for home gavage-feeding, of which 52 (including five sets of twins) participated. The evaluation focused on

infant outcomes, including readmissions, on cost savings and on parental satisfaction.

Greenhough (2004) also undertook a retrospective review of the care offered to neonates born at less than 32 weeks of gestational age who were admitted during the first week after birth to one of four neonatal intensive care units (NICUs), who subsequently developed chronic lung disease (CLD) and who survived until discharge. The intention was to judge whether the health care utilisation and costs of these babies were higher in their first two years when they were discharged from NICUs that made more use of home oxygen (for more than 50 per cent of discharges), compared to those discharged from NICUs that made restricted use of home oxygen. An implicit hypothesis seems to have been that NICUs making greater use of home oxygen were effectively operating early discharge. Retrospective record review was used to assess health care use and costs.

Nature of intervention

The home gavage-feeing scheme evaluated in Sturm (2005) was managed from a single hospital. The babies had to satisfy a range of clinical criteria, and have families who satisfied additional criteria, such as ability and willingness to participate, to be included. All but four of the families in the study were supported by home nursing services that monitored the babies' progress, addressed parents' concerns, and assisted the transition to full oral feeding. Families could also call the NICU for advice or with any concerns.

In the Greenough (2004) study, there were no staff dedicated to providing generic support to babies discharged home with oxygen, but the high use centres did have staff who worked as 'home oxygen specialists' (p. 293).

Cost data collected

Sturm (2005) reported the number of readmissions and in-patient days saved, to which the hospital NICU charges were applied to calculate average savings per baby.

Data used for Greenhough (2004) had been collected for an earlier study (Greenhough *et al*., 2002). Data covered neonates' hospital stay, including drugs, from the neonatal admission records, data about out-patient visits from GP records, and the use of healthcare resources at home including consultations with their GP, referrals to a health visitor or community paediatrician, the use of home oxygen services and the use of community support services. Costs were assessed over a two year period.

For each hospital admission, data were collected on whether the neonate was cared for on a paediatric ward, or in a high dependency unit or an intensive care unit, and their length of stay, to which the relevant per diem cost was applied. The per diem costs of the specialist units were obtained directly from the four centres, whereas the costs of general paediatric wards were derived from UK NHS reference costs. Out-patient attendances were calculated by assuming 15 minutes per attendance to which was applied the average cost from the four centres. Costs for GPs and community based

staff were calculated using net remuneration rates to which were added the appropriate overheads including national insurance and superannuation, capital, travel and expenses. It is not clear whether these costs were calculated by the researchers or whether they were taken from a secondary source which uses similar methods to calculate standard costs for hospital, community and primary care staff. Drug costs were taken from British National Formulary prices. Readmission rates, length of stay and utilisation of resources were reported in both studies, and costed activity was combined to provide summary costs.

The costs associated with 'normal' health care utilisation by babies and children, such as health visitors and immunisation were not included. No costs were calculated for the burden on the family, for example loss of earnings.

While Greenhough *et al*. (2002) presented detailed data, the study included here (Greenhough, 2004) reported only the total costs of neo-natal care, care after discharge from the NICU, and total costs, calculated in the earlier study. Some service use data were also reported but, again, less than in the previous study (see Table 78).

Table 78. Types of use and cost data reported

Data reported	Greenhough (2004)	Sturm (2005)
Cost of neonatal care	Yes	Yes
Cost of hospital care after discharge from NICU	Yes	Yes
Total costs	Yes	-

Reported costs of care

Sturm (2005) reported a charge for the NICU of $1002 per day, which included room, physician, nursing and monitor charges. Average savings to third-party payers were calculated. Four families were self-payers. The average hospital length of stay for the home gavage group was 23.6 +/- 18.6 days compared to 31+/-25.6 days for those discharged on full oral feedings. There were ten readmissions for the home gavage-feeding infants, none of which were thought to be related to the gavage-feeding.

Table 79 shows the reported total neo-natal care costs, total costs after discharge from the NICU, and total costs, comparing infants discharged from units using high levels of home oxygen compared to those with restricted home oxygen use taken from Greenhough (2004). Care in the neonatal period and total costs were significantly lower for centres making high use of home oxygen, but the difference in care costs after discharge from the NICU was not statistically significant.

Table 79. Cost of care related to use of home oxygen (Greenhough, 2004)

	Type of unit	
Type of cost	**Units with high home oxygen use (n=119)** **Mean/ median (range)**	**Units with restricted home oxygen use (n=116)** **Mean/ median (range)**
Neonatal care	24600[a.] 8100-127800	39116[a.] 12726-328500
Care after discharge from NICU	3619 423 – 85831	3142[b.] 95-58444
Total costs	n/a 28965 11098-139267	n/a 43555[a.] 14671-330213

a. p< 0.0001.

b. p= 0.3396.

Economic analysis

Sturm (2005) calculated that the 52 infants in the home gavage scheme were discharged on average 10-12 days earlier than infants discharged having achieved full oral feeding. They had 645 fewer hospital days than an equivalent group of hospitalised infants, resulting in average savings of $12,428 per infant. These savings would accrue to third-party payers and to the four families who self-paid. It was also suggested that some families might have saved on insurance co-payments (not calculated). Parents were satisfied with their participation in the scheme. However, the study recognises that only 36 of the infants and families suitable for home gavage-feeding used the scheme and therefore probably only the 'best' candidates may have been selected.

Greenhough (2004) shows that centres that sent home a high percentage of premature babies home with oxygen performed similarly to centres where only a small percentage of babies were sent home with oxygen. The use of antenatal steroids was higher in the home oxygen group, but duration of neonatal stay, number of GP appointments and community care contacts were lower. As we saw above, the total costs for the high home oxygen usage centres were significantly lower than the costs for the low home oxygen usage centres. Much of the benefit in costs in centres with a high rather than restricted use of home oxygen therapy is probably explained by high use centres discharging babies home, on average, 18 days earlier. There was also some suggestion that the centres offered different care packages during admission, resulting in differing healthcare resource utilisation. However, the authors also comment that the impact on the families of increased use of home oxygen therapy should be considered, as a small survey if families found that mothers of infants receiving home oxygen therapy had less vitality and more mental health problems than those who were not.

6.2 Home care for children with diabetes

6.2.1 Types of study

Three papers, all describing the same home diabetes service, at different stages of development, were included here. Kirk (2003) examined the cost effectiveness of the original service, whilst McEvilly (2005) examined the cost effectiveness of the extended service. The same cost data used in Kirk (2003) were also used in Kirk (2006) and thus add nothing to the economics analysis. The purpose of the studies was to demonstrate the ongoing and benefits to be derived from a home diabetes service, building on the findings of an earlier study undertaken in 1984.

6.2.2 Nature of the intervention

The papers focused on hospital based and 24-hour home care based management for newly diagnosed and existing diabetes. The service started in one hospital and was later extended to another. Paediatric diabetes specialist nurses (PDSNs), who made home and school visits, and gave telephone advice, for example on medication, supported the service.

6.2.3 Cost and resource data collected

The costs and resource data reported in the papers are shown in Table 80. Both examined the effectiveness of the diabetes home care service over its 20 year history. Kirk (2003) collected data on workload of the PDSNs, later updated in McEvilly (2005) which provided data for the extended service. These data demonstrated the breadth of the service's work and its potential capacity, although there was no discussion about the efficiency and comparative costs of the staff, upon whom the success of the service depended.

Readmission rates were calculated for new and existing patients and the trend over time was shown graphically, demonstrating that re-admission rates and total in-patient bed-days fell over time, that many of the newly diagnosed children had been entirely home managed, and that length of hospital stay had also fallen.

Costs were given only for in-patient bed days and the PDSNs although the source of these costs was not provided. McEvilly (2005) provides activity data for the whole diabetic home care unit, but not costs. The study is thus limited in respect of its costing methodology.

Neither paper reports costs for families and other agencies.

6.2.4 Reported activity and costs of care

Most of the data presented are activity levels of the service, as shown in Table 81. Kirk (2003) reported the number of visits undertaken by the PDSNs, whilst McEvilly (2005) provided data on activity for the whole unit. Kirk (2003) reported actual data whilst McEvilly (2005) provided data in

graphical format only. This makes it impossible to ascertain data for points in time, only trends, and those results discussed in more detail by the authors.

6.2.5 Economic analysis

All studies were effectively cost minimisation studies as they calculated only the savings from the reduction in bed days associated with patients being managed at home, lower re-admission rates and shorter lengths of stay. Kirk (2003) estimated the savings from reduced bed days in 2001 to be £15,110 compared to the cost of the PDSN at £14,800. McEvilly (2005) calculated a saving of 705 bed days a year for the whole service (based on 35 newly diagnosed and 350 existing patients), giving a potential saving of £355,500 per year, which is greater than the cost of the home care unit. The reasons why there were great differences in activity levels and bed days between the studies, given that they were evaluating the same service, were not explained. Further, as discussed in Chapter 4, at least some of the reduction in bed days may have been due to secular change

All studies used changes in HbA_{1c} levels as the outcome measure, but did not combine with cost data to produce a cost per unit of reduction in HbA_{1c}.

Table 80. Type of cost and resource data collected under alternative models of care for children with diabetes

Data collected	Kirk (2003)	McEvilly (2005)
No of home visits/ diabetic specialist nurse:		
Total	Yes	Yes
Routine	Yes	Yes
emergency	Yes	Yes
No of:		
School visits	Yes	Yes
HCU visits	Yes	Yes
Ward visits	Yes	Yes
No of:		
Clinic visits	Yes	Yes
Young adult clinic visits	Yes	Yes
No of patient contacts	Yes	Yes
No of		
Newly diagnosed patients per annum	Yes	Yes
Wholly home managed patients	Yes	Yes
Mean bed-days per		
New patient	Yes	Yes
Existing patient	Yes	Yes
Cost per in-patient bed-day	Yes	Yes
Cost per wte G Grade PDSN	Yes	No
Diabetic control: fall in HbAI	Yes	Yes

Table 81. Activity, cost and outcome data collected

Data collected	Kirk (2003)[a.]	McEvilly (2005)[b.]
Total patient numbers	No of visits/ diabetic specialist nurse*:	Total workload of diabetic home care unit
Total home	-	350
Routine home	127	748
Emergency home	119	567
School visits	8	181
HCU visits	12	94
Ward visits	2	-
Clinic visits	23	206
Young adult clinic visits	167	986
Department visits	51	-
Drop-in	-	321
	-	156
No of patient contacts*	604	-
No of Newly diagnosed patients: total (1995 onwards) Newly diagnosed patients per annum (range) Wholly home managed patients: total	 36 5 (3-9) 5	 31 - 12
Mean bed-days per new patient	2.0	2.0
Mean bed-days/DHC patient	-	0.2
Mean readmission rates per annum (bed-days) for existing patients (1997-2001) (range)	15.2 (12-23)	-
Mean readmission rates per annum (bed-days) for existing patients (2001-2)	37	-
Reduction in bed-days since service established New patients per year Existing patients per year	 21.5 42.8	 77 628
Cost per in-patient bed day	235	500
Cost per wte G Grade PDSN per annum	£14,800	-
Diabetic control: mean HbAI	8.95	9.00-9.3

a. Annual data is provided for 1997/8 to 2001/2. Table 22 shows data for 2001/2 only.

b. Data for 2003.

6.3 Home care for children with mental health problems

6.3.1 Types of study

A single study was included in this category. Carson (1998) compared the clinical and cost effectiveness of home based care with hospital-based care

for children with psychiatric illnesses. Fifty-four children and young people were included in the study. Outcomes were measured by compliance levels and achievement of the goals of treatment plans.

6.3.2 Nature of the intervention

The RESTORE programme evaluated in Carson (1998) comprised intensive one-to-one interaction between a variety of professionals and the child in their own home. It included home health care nurses educating patients and primary care givers on implementation of a behavioural plan. Patients were referred on discharge from in-patient psychiatric care.

6.3.3 Cost data collected

Data were collected on time spent in the home care programmes, as shown in Table 82, including the costs of the home health care nurse and per diem costs of comparative care in hospital. Although patients also saw physicians and counsellors, had case managers, and attended clinics, these resource data are neither quantified nor costed.

Family costs were not collected, nor were other societal costs, for example, those associated with the criminal justice system for children who came into contact with it.

Table 82. Type of cost data collected (Carson, 1998)

Data collected	
Home care/case	Yes
Foster or residential care	-
Hospital per diem	Yes
Home health nurse visits	Yes
No of days	Yes
Total costs	Yes

6.3.4 Reported costs of care

As shown in Table 83, Carson (1998) provided the per diem costs of the in-patient care, compared with the total costs of home care. However, the total costs of an average case managed under in-patient care were not calculated, although length of stay was provided, to which average per diem costs could have been applied. Eleven children were re-hospitalised for psychiatric reasons, but these costs were not calculated, nor were the costs associated with those were discharged for persistent non-compliance.

6.3.5 Economic analysis

Carson (1998) claims that the RESTORE programme led to substantial savings in costs when compared to conventional in-patient care. The

programme also led to high levels of compliance with medication and two-thirds of patients achieved the goals of their treatment plans.

Table 83. Average costs under alternative models of care (Carson, 1998)

Costs of different types of care			
In-patient care		Home care	
Per diem	$500	Per nursing visit	$65-$115
No of days	35	No of days	35-36
		No visits	10-11
Total cost	$17,500	Total cost	$650-$710

6.4 Admission avoidance and early discharge for children with acute conditions

Two different types of studies are included in this section. First, there were two studies of home care schemes specifically designed to provide acute care for children with a range of conditions at home, as an alternative to hospital care. As has become common in the UK, these are known as 'hospital at home' schemes.

Secondly, there was a study of care for specific acute needs (in this case, and in Chapter 4, fractures) where different approaches meant that children might be able to be cared for at home rather than in hospital for all or part of their treatment.

We present material from both types of study in this section, but review them separately.

6.4.1 Admission avoidance and early discharge for generic acute conditions

Types of study

Two studies were included in this category.

A study by the University of Warwick (nd, called hereafter 'the Warwick study') examined the impact of two children's hospital at home (HaH) services. The evaluation comprised a before and after comparison with a case control comparison (a similar geographic area) and was undertaken in two phases. The report reviewed here focuses on the phase II results. Four hundred and sixty-six children resident in Rugby who attended the paediatric assessment unit at the Walsgrave Hospital and/or were admitted to the in-patient ward, between August 2000 and February 2001 formed the sample. Data was also analysed for the first nine months activity of the HaH service, between June 2000 and March 2001.

In the second study included here, Bagust (2002) compared the costs of children managed by a children's HaH service with those managed in a traditional hospital setting, as part of an RCT. The privately borne and NHS costs of the HaH and conventional in-patient care for children with selected

acute conditions were compared. Children were randomised following admission to the medical assessment unit; those with certain types of breathing difficulties, diarrhoea and vomiting, or fever were eligible for management by the HaH. Three hundred and ninety-nine children were included in the study and a sub-sample of 40 families were selected for in-depth interview about their satisfaction with HaH and hospital care. The principal outcome measure for the economic evaluation was readmissions. A cost minimisation approach was taken.

Nature of intervention

The HaH scheme in the Warwick study aimed to limit or prevent admission to hospital, to facilitate early discharge, and to enable acutely ill children to be cared for at home. The service provided nursing care and operated between 8.00am and 10.00pm, seven days a week. Outside these hours, there was telephone on-call cover. Referrals to the HaH came from GPs, from local acute hospitals and assessment units and a local A&E service.

The HaH scheme evaluated in Bagust (2002) was for children who were assessed as likely to need at least 24 hours of nursing observation after assessment in an acute paediatric setting, after which they would be discharged home. Nursing care was provided for 24 hours a day, seven days a week, with planned care up to 11.00pm and an on-call service during the night. The nurses provided support and care for the children and their families while at the same time 'educating and empowering parents to care for their child' (Sartain *et al*., 2002: 372).

Data collected

The Warwick study collected routine admission data and data on severity and resource use. Data on parental satisfaction and the impact of the child's admission to the HaH or hospital on the family were collected. Parents also participated in telephone interviews to validate data about the current episode of illness, and to obtain qualitative information on the acceptability of services. Routine cost data was collected from the hospital finance department. An average cost per day was used, which was calculated under a set of assumptions including number of beds on the ward, staff time spent with children, diagnostic tests and consumables, and other overheads. Two sets of costs were calculated under different assumptions about bed numbers. The costs of the HaH were also calculated. The cost per in-patient day was taken from published data.

Bagust (2002) collected data on health services resources utilised, including in-patient days per index admission, subsequent readmissions for related conditions within 90 days, days of HAH care provided, home visits made and their duration, and distance travelled per visit. They also collected data on the burden on families by means of a questionnaire assessing private expenditure and absences from work. Direct costs falling on the families included travel to hospital, additional food, phone calls and child care. All costs calculated are shown in Table 84.

Table 84. Type of cost data collected

Data collected	University of Warwick (nd)	Bagust et al. (2002)
Hospital in-patient cost per day	Yes	Yes
In-patient paediatric assessment unit	Yes	-
Hospital days	Yes	Yes
Total hospital costs	Yes	Yes
Total HaH salary costs	Yes	Yes
HaH travel costs	-	Yes
HaH other costs (on-call + telephone)	-	-
HaH cost per visit	-	-
HaH cost per case	-	Yes
HaH cost per day	Yes	-
Journeys to hospital	-	Yes
Mean fares paid	-	Yes
Travel costs	-	Yes
Mean food cost	-	Yes
Other family costs	-	Yes
Total direct family costs	-	Yes

Reported costs of care

Because the two studies calculated a different set of costs, separate tables are presented for each.

The Warwick study reported a range of costs under a variety of assumptions as shown in Table 85. Differences in costs were reported for the two time periods (i.e. before and after implementation), the main differences being the fall in total care costs for children of £24,147 (a 23 per cent fall), and the costs of care on the main paediatric ward of £23,681 (24 per cent fall). However, the cost of the HaH was calculated as £163,000.

Bagust (2002) calculated the costs falling on the NHS and on the families, shown in Table 86. Using a cost of £368 per in-patient day, and an average length of stay of 2.01 days for those in receipt of in-patient care and 0.40 days for those managed by the HaH scheme, the cost of children managed in in-patient care was £741 and £147 for the HaH scheme. This implies a net reduction of £593 per patient. The cost of the HaH team was estimated to be £148,000 under a given set of staffing assumptions. However, because of the slow take-up of the service, full staff levels were not achieved, and the actual costs of the HaH during the evaluation period were lower. The average cost per case for HaH was £741, of which £707 was

salary costs. If a 50 per cent increase in throughput is assumed, however, the salary costs would be reduced to £470 per case. Total costs to the family were calculated to be £23.31 for those whose children had in-patient care, and £13.76 for HaH care. The costs associated with parental working time lost (similar for families across the two groups) were not calculated. Assessing burden of care, from diaries completed by 125 families, there was no evidence that HaH transfers a burden to families.

Table 85. Average costs under alternative models of care (Warwick study)

Data collected	
Hospital paediatric in-patient cost per day	£310
Paediatric assessment unit referral	£6247 (1999/00) £5881 (00/01)
Total hospital costs (assessment unit + ward care) over study periods	£106,352 (1999/00) £82,205 (00/01)
Difference in total acute care hospital costs	£24,147 (22.7 fall)
Difference in paediatric assessment unit costs	£366 (6 fall)
Difference in main ward hospital costs	£23,681 (23.7)
Total HaH salary costs	£162,581
HaH cost per day	£445.43
Total costs of care (acute + HaH) for study period (00/01)	£176,636
Extrapolated annual total costs of care	£304.114
Total increase in total costs	£121007

Table 86. Average costs under alternative models of hospital care (Bagust, 2002)

Data collected	In-patient care	Hospital at home	Significance
Hospital in-patient care per day	£368	£368	-
Hospital days	2.01	0.40	-
Total hospital costs	£741	£147	-
Total HaH salary costs	-	£148,000	-
HaH cost per care	-	£707	-
HaH Travel costs per case	-	£16	-
Journeys to hospital	5.3	3.05	$p<0.0001$[a.]
Mean fares paid	£10.04	£8.25	$p=0.59$[b.]
Mean total travel costs	£21.42	£15.15	$p=0.007$[a.]
Mean food cost	£9.23	£6.34	$p=0.09$[b.]

Mean cost of phone calls	£0.87	£0.69	p=0.62 [b.]
Childcare costs	£2.24	£0.12	p=0.047 [b.]
Other family costs[c.]	£1.17	£0.55	p=0.31 [b.]
Total family costs	£23.31	£13.76	p=0.001[a.]

a. t test of means with unequal variance.

b. t test of means with equal variance.

c. Excludes £130 holiday cancellation cost.

Economic analysis

The Warwick study demonstrated a six per cent fall in the total number of referrals to the paediatric assessment unit, although the number of GP referrals rose by seven per cent. Number of admissions to the in-patient ward fell by 20 per cent and length of stay fell from an average of 2.13 to 2.03 days; as a result, total occupied bed days fell by 24 per cent. A greater proportion of those admitted to in-patient care were classified as having a 'medium type illness', probably reflecting that less severely ill children were being managed by the HaH. The number of referrals to the HaH increased greatly from all sources, including GPs. However, although there was a 24 per cent reduction in acute care costs, the authors observed that most of these would not be able to be realised under the commissioning and providing regime that obtained at the time.[i] As a result, the cost of the HaH was significantly greater than the savings by an estimated £120,000, an increase of around 66 per cent. This study also considered the burden on families, and reported that there was increased parental satisfaction and a reduction in the disruption to children and families associated with ill health and financial savings to families when care was provided through HaH. However, these benefits were not quantified.

Although Bagust (2002) envisaged undertaking a cost effectiveness study, because the prime clinical outcome (readmission rate) did not differ significantly between the two groups of children, a cost minimisation analysis was undertaken instead. Taking the total costs of a child managed in hospital care compared to those managed within the HaH scheme (taking into account the costs of running the HaH scheme), the study assessed that total NHS costs appeared to be £130 per case higher for HaH care than for hospital care. These results were highly sensitive to the unit cost per day and the throughput of the HaH service. Using national average costs gave a cost difference of £165, whilst assuming a 50 per cent greater throughput gave a saving of £107 (using local costs) or £72 (using national costs). The direct costs incurred by families were usually low and were either similar across the two groups or lower for the HaH group. Therefore, under certain assumptions about throughput which, as the authors comment, would require careful planning and implementation, HAH may be a little cheaper

[i] Under payment by results, however, it is possible that these savings would be realised.

than traditional hospital based care, is preferred by families and appears to place little or no additional financial or caring burden on them.

6.4.2 Home care for specific acute need

Types of study

One cost effectiveness study was included in this category. Hedin et al. (1983) compared the costs and outcomes for children with femoral shaft fractures admitted to one of three county hospitals in Sweden. One of these hospitals used home traction as part of its treatment regime.

Nature of intervention

At hospital one, treatment comprised external fixation and early mobilisation; at hospital two, treatment comprised skin or skeletal traction in hospital followed by home traction; and at hospital three treatment comprised skin or skeletal traction in hospital until the fracture healed. For our review, it is the comparison between hospitals two and three that is relevant and is reported here.

Cost and resource data collected

The cost and resource data collected are shown in Tables 87 and 88. The hospitals' finance departments calculated unit costs for each part of the treatment: overall costs were very similar as they were calculated in the same way. Cost estimates were based on consumption in previous years, and no capital costs were included. All costs were calculated from the time of injury up to one year after and included costs of treatment and complications thereafter. The resulting average costs for the elements of in-patient and out-patient care are shown in Table 89.

Impact on parental employment was calculated in two ways: using the number of days away from work that parents reported in questionnaires (type 1), or using the number of days recorded at the regional social insurance office as sick-leave for taking care of the child (type 2). Loss of earnings associated with taking care of the child was calculated using the published salaries and wages in the Swedish Statistical Yearbook.

Table 87. Type of cost data collected under alternative models of care (Hedin, 2004)

Financial data collected	
In-patient cost:	
Per day	Yes
Per minute surgery including anaesthetic and operating theatre costs	Yes
Per radiograph: acute	Yes
Per radiograph planned	Yes
Out-patient cost per visit	Yes
Average monthly parents' salary	Yes
Average total cost per patient, including parental sick leave	Yes

Table 88. Type of resource utilisation data collected under alternative models of care (Hedin, 2004)

Other resource use data	
No of patients, by hospital, by age, gender and cause of injury	Yes
Operation time (minutes) by hospital	Yes
Days in hospital	Yes
Number of radiographs	Yes
Total duration of treatment	Yes
Number of visits to out-patient clinics	Yes
Number of days spent in hospital for parents	Yes
Number of days spent at home for parents	No

Table 89. Average costs of resources utilised under alternative models of care (Hedin, 2004)

Financial data	Cost/ unit: Euro
In-patient cost:	
Per day	706
Per minute surgery including anaesthetic and operating theatre costs	12
Per radiograph: acute	42
Per radiograph planned	33
Out-patient cost per visit	131
Average monthly parents' salary	2529-4077

Reported costs of care

The results for hospitals two and three are shown in Tables 90–92.

Table 90 shows the resource utilisation data for those managed under the alternative models of care.

Table 90. Resource utilisation data for those managed under alternative models of care (Hedin, 2004)

Resource use	Hospital 2 Mean (range)	Hospital 3 Mean (range)
Operation time (minutes)	68 (0-170)	59 (0-125)
Days in hospital	23 (10-49)	44 (27-65)
Number of radiographs	6.3 (4-12)	7.2 (4-11)
Duration of treatment (days)	43 (26-55)	38 (27-54)
Number of visits to out-patient clinics	2.8 (1-6)	2.0 (0-4)

Table 91 shows the length of stay in hospital and home, whether supported by a parent who took time off work (the costs of which are included in the

overall cost of the patient's treatment). Patient satisfaction was also recorded.

Table 91. Quantification of parental support and satisfaction levels under alternative models of care (Hedin, 2004)

Level of parental support and satisfaction	Hospital 2	Hospital 3
Days in hospital: Mean (range)		
Supported by mother	16 (5-49)	30 (0-65)
Supported by father	4.6 (0-21)	15 (0-45)
Days at home: Mean (range)		
Supported by mother	36 (0-120)	43 (0-84)
Supported by father	7.8 (0-32)	16 (0-47)
Patient satisfaction: (n, %)		
Yes	11 (48%)	12 (75%)
No	12 (52%)	4 (25%)

The costs of care under the alternative models are shown in Table 92.

Table 92. Average costs of alternative models of care (Hedin, 2004)

Type of costs	Hospital 2 Mean Euros (95% CI)	Hospital 3 Mean Euros (95% CI)
In-patient care		
Days of care	16100	30750
Surgery	(10730-21470)	(27520-33990)
Radiographs	710 (490-940)	750 (580-910)
	60 (50-70)	40 (30-50)
Visits to out-patient clinic	370 (270-470)	260 (200-330)
Costs of parental leave (1)	5730 (4720-6740)	6490 (5520-7470)
Costs of parental leave (2)	2530 (1540-3530)	2490 (1690-3290)
Total costs (with type 1 leave)	22980	38300
Total costs (with type 2 leave)	(17430-28530)	(34600-41990)
	19780	34280
	(14560-24990)	(30950-37620)

Economic analysis

The mean total cost of treatment (including costs of type 1 parental leave) at hospital 2 was 22,980 Euros, and at hospital 3 was 38,300 Euros. The mean total cost of treatment (including costs of type 2 parental leave) at hospital 2 was 19,780 Euros, and at hospital 3 was 34,280 Euros. The study thus showed that total costs for the group receiving home traction were around half of those using in-hospital traction (Hedin, 2004: 247) without imposing additional costs on families.

6.5 Home chemotherapy and home care for complications

6.5.1 Type of study

Two studies were included here. One (Stevens, 2006) was specifically about the delivery of chemotherapy at home and one about home care management of febrile neutropenia (NP) for children who also received their chemotherapy at home (Raisch, 2003).

Stevens (2006) was a randomised crossover trial involving 23 children with acute lymphoblastic leukaemia (ALL) in Canada. The study compared hospital and home based chemotherapy in relation to quality of life, carer burden and costs. Fifty-nine patients aged 2-16 fulfilled the eligibility criteria, of whom 29 were consented to participation. Of this group, 13 were allocated to the home then hospital group and ten to the hospital then home group. Use of the crossover design allowed children to serve as their own controls.

Raisch (2003) was a retrospective cohort study of in-patient and home-care management of children with FN, using record review. Children aged between one and 19 with low risk characteristics were eligible. Data were collected about 27 children (with 72 episodes of FN) who received hospital-based management and 36 children (with 72 episodes of FN) who received home-care based management.

6.5.2 Nature of interventions

Home chemotherapy in Stevens (2006) involved a community pharmacy preparing and delivering chemotherapy drugs to the child's home. At a convenient pre-arranged time, a trained nurse from a community health services agency visited to administer the drugs. Some children in home treatment who were receiving particular drugs or modes of administration did receive these in a paediatric oncology clinic, for safety reasons. Hospital chemotherapy involved all chemotherapy being administered by a trained nurse during a child's scheduled out-patient visit to the hospital oncology clinic, following which the child was discharged home.

The children in the Raisch (2003) study were treated in two different centres; those managed on the home-care programme also received their chemotherapy through an established home-care programme. There are no details about the service content of the home care programme in the published paper.

6.5.3 Cost data collected for the studies of the management of children with cancer

Data collected in the studies are shown in Table 93.

In Stevens (2006), data were collected at baseline (time 1), 3 months into phase 1 (time 2), the end of phase 1 (time 3), 3 months into phase 2 (time 4) and the end of phase 2 (time 5). Quality of life was measured using the

Pediatric Oncology Quality of Life Scale (POQOLS) and the Child Behaviour Checklist (CBCL). Burden of care was measured using the Caregiving Burden Scale (CBS). Costs, from a societal perspective, were collected using the Health Service Utilisation and Costs of Care Inventory (HSUCCI). This instrument asks participants to recall the use of services: visits to physicians and other care providers; direct out of pocket spending on medications and supplies, travel and child-minding; and indirect costs such as lost income and productivity associated with caring for the child. Societal costs excluded the costs of the chemotherapy and its administration.

Raisch (2003) collected demographic data, diagnosis and clinical data. Data on health care utilisation included antibiotics, supportive medication, number of hospital days, number of intensive care unit days, physician visits, out-patient visits, emergency room visits, home-care visits, diagnostic tests and laboratory tests. Data were collected directly from patient charts. Non-medical resources and outcomes were not considered, although the authors acknowledge this and recommend that these costs and outcomes need to be considered to ensure that the full impact of home-based treatment of FN can be evaluated.

Table 93. Type of cost data collected

Data collected	Stevens et al. (2006)	Raisch et al. (2003)
Hospital in-patient care	-	Yes
Pathology tests	-	Yes
Radiology procedures	-	Yes
Medications	-	Yes
Physician visits	-	Yes
Home care	-	Yes
Total costs	Yes	Yes

6.5.4 Reported costs of care

As summarised in Table 94, Stevens (2006) calculated the total costs of services used by multiplying utilisation data reported by parents by the estimated average health and social services unit costs for the province of Ontario. Total societal costs (median) were higher for the home group (Can$1795) than the hospital group (C$1374) at time period 1, but were lower at time period 2 (Can$1318 and Can$1409) and time period 3 (Can$851 and Can$1050), though none of the differences was statistically significant.

Table 94 shows utilisation for all the healthcare resource variables under the two models of care being compared in Raisch (2003), and Table 95 the charges associated with the health care resources. Mean total charges for hospital-based treatment are higher than those for home based treatment (US$11,236 compared to US$6,081). Mean charges associated with hospital days were considerably higher for those having hospital based (US$5,826) compared to home based (US$101) treatment, and mean charges

associated with home-care days were considerably lower for those having hospital-based (US$456) compared to home based (US$1,529) treatment. Mean charges for antibiotics were similar for both groups (US$2,375 compared to US$2,523) whilst median charges were statistically different (US$1,526 compared to US$2,523). The three most expensive health-care resources in the hospital-based group were hospitalisation, antibiotic use and filgrastim charges. The three highest expenses in the home care-based group were antibiotic use, home-care visits and filgrastim charges. Charges for diagnostic tests did not have a large impact on total costs in either setting.

Table 94. Average annual costs under alternative models of care (Stevens, 2006)

Data collected	All	Home	Hospital
Total costs (Time 1)	N=29	N=15	N=14
Median	1457	1795	1374
Range	98-7227	327-7227	98-4381
Total costs (Time 3)	N=25	N=14	N=11
Median	1323	1318	1409
Range	298-7342	298-6302	419-7342
Total costs (Time 5)	N=22	N=13	N=9
Median	859	851	1050
Range	29-10278	147-8726	29-10278

Table 95. Average annual costs under alternative models of care (Raisch, 2003)

Healthcare resource variables	Hospital based treatment		Homecare based treatment	
	Mean (SD)	Median	Mean (SD)	Median
Blood cultures	1.7 (0.5) p=0.004	2	1.9 (0.3) p=0.004	2
All cultures	4.7 (2.0) p<0.001	4	3.4 (0.7) p<0.001	3
Microbiology studies	3.3 (2.3) p<0.001	3	1.5 (0.7) p<0.001	1
Complete blood counts	6.1 (3.0) p=0.001	6	4.4 (1.6) p=0.001	4
Platelet counts	6.0 (3.0) p=0.002	6	4.5 (1.7) p=0.002	4
Manual differentials	5.8 (3.0) p=0.002	5	4.4 (1.6) p=0.002	4
Serum chemistries	3.0 (2.8) p<0.001	2	1.0 (1.2) p<0.001	1
Clinic visits	0.5 (0.5) p<0.001	0	1.7 (1.3) p<0.001	2
Home-care days	2.3 (3.2) p<0.001	0	7.1 (2.8) p<0.001	7
Hospital days	6.4 (3.1) p<0.001	6	0.1 (0.5) p<0.001	0
Physician visits	6.6 (3.3) p<0.001	6	1.0 (1.0) p<0.001	1
Six-pack platelet transfusions	0.9 (1.0)	1	0.7 (1.1)	1
PRBC transfusions	1.4 (1.3) p=0.015	1	0.9 (1.1) p=0.015	0
TPN days	1.5 (2.9) p<0.001	0	0.2 (1.5) p<0.001	0
Patient outcome variables				
Intensive care unit days	0 (0.1)	0	0.1 (0.5)	0
Intravenous antibiotic days	6.3 (3.1) p=0.008	6	7.6 (2.6) p=0.008	8
Total no antibiotic days (intravenous + oral)	7.3 (3.6)	6.5	8.3 (2.7)	8.0
Number (%) successful episodes	72 (100)		72 (100)	

Table 96. Average annual costs under alternative models of care (Raisch, 2003)

Healthcare resource variables	Hospital based treatment		Homecare based treatment	
	Mean (SD)	Median	Mean (SD)	Median
Blood cultures	127 (35)	150[a.]	142 (24)	150 [a.]
All cultures	279 (96)	250[b.]	215 (38)	200 [b.]
Microbiology studies	23 (60)	0[b.]	0	0[b.]
Complete blood counts	121 (60)	198[c.]	89 (32)	148[c.]
Serum chemistries	266 (248)	182[b.]	83 (104)	81[b.]
Clinic visits	24 (25)	0[b.]	83 (67)	100[b.]
Home-care days	456 (691)	0[b.]	1529 (670)	1554[b.]
Hospital days	5826 (2810)	5460[b.]	101 (496)	0[b.]
Antibiotics	2375 (2452)	1526[d.]	2523 (1332)	2523[d.]
Platelet transfusions	75 (84)	84	58 (91)	42
PRBC transfusions	112 (126)	126	88 (136)	63
Physician visits	460 (230)	420[b.]	29 (69)	0[b.]
TPN	269 (511)	0[b.]	32 (272)	0[b.]
Aminoglycoside levels	18 (42)	0	1 (4)	0
Vancomycin levels	26 (41)	0[b.]	0	0[b.]
Chest x-ray	54 (85)	0[b.]	12 (38)	0[b.]
CT scan	110 (297)	0[c.]	0	0[c.]
Intensive care unit days	18 (150)	0	141 (695)	0
Filgrastim	622 (878)	451[b.]	1023 (740)	1085[b.]
Total charges	11,236 (6,372)	9,392	6081 (2653)	5893[b.]

a. p= 0.004; b. p< 0.001; c. p= 0.001; d. p= .019

6.5.5 Economic analysis

Stevens (2006) demonstrated that there was a quality of life gain for children in switching from a hospital-based to a home-based regime. Age was a factor, with scores for older children being better. However, costs associated with the two regimes (other than the costs of the treatment and its administration) were similar. The model of home chemotherapy was seen as a new venture with challenges to be overcome, for example, in organising the services and developing partnerships with the laboratories that served the adult population. Whilst the authors believe that home chemotherapy was a possible option for the management of a child's treatment, they acknowledged that overcoming the organisational challenges might be costly, and would have to weighed against any potential benefits to be realised.

In the Raisch (2003) study, the difference in total charges per episode between hospital based treatment and home-care based treatment was US$5,155 and US$3,499 for mean and median charges. Total savings associated with home care management, assuming 72 episodes of febrile neutropenia was $371,160 (using mean values) and $251,928 (using median values). The authors undertook sensitivity analysis on their results: decreasing median total charges in the hospital-based group would have the greatest impact, yet even under this scenario, savings with home care would still be around $1,100 per treatment. Under break-even sensitivity analysis, median home-care charges were 63 per cent of hospital charges.

6.6 Technological care at home, including dialysis

Two different types of studies are included in this section. First there are three studies of CCTH for children who were dependent on technology for most or all of the day and night and one of those who use technology intermittently, in this case for home dialysis. We present and review these two sorts of studies separately.

6.6.1 Home care for technology dependent children (24-hour care)

Type of study

Three studies were included in this section; two examined the costs of alternative models of care delivery while the third examined the cost effectiveness of alternatives.

Nature of the intervention

Stutts (1994) examined the impact of prescribed childcare centres (also known as medically fragile day centres and facility-based care), developed as an alternative to prolonged hospitalisation for technology dependent children and a supplement to home care alone. The centre provided a wide variety of services, to children aged three or more, including skilled nursing care, developmental programmes and parental education. It was open

Monday to Friday, during the day, and attendance was 'prescribed' by a physician for children who were medically fragile and/or technology dependent. Nine families participated in a study examining a variety of outcomes associated with the use of this centre. Six families received home care services only, one received prescribed child care services but no home care services, and two received both prescribed child care and home care services.

Fields (1993) evaluated the long-term outcomes of children in vegetative states cared for at home. All patients had their home care co-ordinated by the Co-ordinating Centre for Home and Community Care (CCHCC), a subcontractor to the Medicaid Model Waiver Program, which was responsible for case management, monitoring care plans and determining the cost effectiveness of each recipient's programme. Twenty children who were severely neurologically impaired and had a discharging physician's diagnosis of persistive vegetative state or coma at discharge from a tertiary centre were included in the study from 686 children on the CCHCC database.

Noyes (2006) describes the resource use and costs involved in supporting ventilator dependent children and young people at home compared to management in hospital Thirty-five index children were selected from the caseloads of 11 UK hospital consultants who specialised in the management of these children. A purposive sampling strategy was then used, ensuring that children aged between 0-5, 6-12 and 13-18, boys and girls, and those who were managed in home, hospital, and social care settings were represented. The study reports findings in respect of 24 children being managed at home.

Cost data collected for studies of technologically dependent children

Tables 97 and 98 show data collected and average costs of care under alternative models.

Stutts (1994) collected qualitative data on parental satisfaction and their feelings and concerns, and on monthly hours and costs for nursing care in homes and prescribed child care centres.

Fields (1993) collected data on long-term outcomes, personnel requirements, carers' satisfaction with home care, technologies used, and costs. Outcomes included survival at home, death at home or permanent rehospitalisation: analyses grouped patients according to these categories. Home care costs and alternative institutional costs were projected using individualised care plans. The plan detailed all foreseeable care for the following year, regardless of the medical setting, including personnel requirements, technology requirements, acute hospital care, case management, out-patient care, medications, durable medical equipment, disposable medical supplies, transportation, adaptive equipment, and other therapies such as occupational, physical and speech therapy. Actual costs averaged 76 per cent of this projection.

Noyes (2006) collected data via interviews with parents (and occasionally children) using prompt cards on services received as well as current

accommodation and use of transportation, employment and income received. A societal view was taken. For services received, nationally published unit costs were applied, adjusted to reflect frequency and duration, to calculate total costs. Other sources of valuation included national data on pay, working conditions and welfare benefits; the NHS Finance Manual; British National Formulary; family sources; market prices and a published study on the use of oxygen. The study perspective was broad and included costs borne by the NHS, social services (excluding housing adaptation costs), education (excluding the costs of mainstream statutory education), and services provided by the non-statutory sector.

Table 97. Types of cost data collected

Data collected	Nursing	Total costs	Hospitalisations	Other professional input
Stutts (1994)	Yes	Yes	Number of hours not costs	-
Fields (1993)	Number of hours not costs	Yes	Number of hours not costs	-
Noyes (2006)	Yes	Yes	Yes	Yes

Table 98. Reported average costs of care under alternative models of care

Study	Alternative models	Average cost of care	Average cost of hospital utilisation
Stutts (1994)	Home	Per month:	-
	Prescribed child care centres	US$4322[1]	
		US$1701[1]	
Fields (1993)	Home	1st year: US$129,000+/- US$51,000	-
		2nd year: US$89,000	
	Hospital	1st year: US$169,000	
Noyes (2006)	Home care + 24 hour care		
	Qualified nurses	£239,855	£18,541
	50 per cent qualified	£200,515	£18,541
	Unqualified nurses	£161,174	£18,541
	Parents as unpaid carers	£46,483	£18,541
	Hospital care in children's ward	£155,158	12 months@£398/day

	Long-term ventilation unit	£301,888	12 months@£800/day
	Intensive care unit	£630,388	12 months@£1700 per day

Reported costs of care

Stutts (1994) reported the average number of nursing hours for each family by category of nurse. The average number of hours across the nine families ranged from 83 to a maximum of 382, and average total costs from $1125.66 to a maximum of $9312.77. The average cost per month for those in home care settings was $4322 and for those in prescribed care settings $1701. Average cost per hour of home nursing care was lower than for prescribed child care ($15.43 compared to $21.76), whilst the average number of hours of home nursing care received per month was higher than hours received in prescribed child care centres (280 compared to 223). All costs were in US dollars. Family burden costs were not reported.

Fields (1993) reported that of the 20 children in a persistent vegetative state evaluated, six died at home and two after rehospitalisation. Of those who died, six had been managed at home for less than a year, one for three and one for five years. Of those who survived after discharge home, two had been managed at home for five years, four for four years, two for three years, one for two years and three for one year or less. Financial, personnel and technology resources were extensive. First year costs were estimated to be $129,000 +/- $51,000 per patient, and second year costs were estimated to have decreased by $32,000 per patient. Thereafter annual cost projections remained stable. All costs are in US dollars.

This study did not provide a financial breakdown of the elements of the projected costs, although there is an estimate of nursing hours required, and a quantification of other resources. First year projected nursing hours were an average of 89+/-25 hours per week, decreasing by an average of 18 hours per week in the second year, and remaining stable thereafter. Additionally, 14 children were projected to receive physical therapy, nine occupational therapy and three speech therapy. Technology support included 18 children with gastrostomies, seven with tracheotomies, seven with oxygen, seven with cardio-respiratory monitors, three with pulse oximeters, and two with mechanical ventilation. Most children required only one (median) hospitalisation per year (range of 0-9). Some 78 per cent of admissions were for acute illnesses, and 22 per cent were elective admissions for re-evaluation or respite care.

Noyes (2006) calculated the service use for each of the 24 index cases living at home, having collected data on mean number of contacts. As shown in Table 99, a wide range of services was covered. The total costs of these services are in Table 100. The study also calculated the costs of seven children and young people who were living in hospital for the previous 12 months, and Table 101 compares the costs for the two groups of children.

Table 99. Service use of 24 index children living at home in previous year (Noyes, 2006)

Service type	Ventilator-dependent index cases living at home		
	% (n) using services	Mean number of contacts	Range
In-patient stay in previous 12 months	75 (18/24)	1.8	1-4
Avge length of in-patient stay (nights)	-	9.7	1-63
Out-pt/A&E contacts in past 3 months	100 (24/24)	-	-
GP (face to face)	62 (15/24)	7.7	1-25
GP repeat prescriptions	87 (21/24)	12	-
Health visitor	100 (7/7)	6.2	1-12
Practice nurse	16 (4/24)	1	-
School doctor	85 (11/3)	1	-
School nurse	100 (13/13)	82	1-90
Community paediatrician	8 (2/24)	2	-
Children's community/district nurse	45 (11/24)	16.5	2-52
Dentist	96 (23/24)	2.1	1-6
Orthodontist	12 (3/24)	2.3	2-3
Optician	8 (2/24)	1.5	1-2
Specialist doctor/surgeon	96 (23/24)	5.5	1-11
Orthotists	12 (3/24)	2.3	1-3
Chiropodist	8 (2/24)	3	2-4
Physiotherapist	62 (15/24)	57.4	2-190
Speech or occupational therapists	50 (12/24)	14.2	2-48
Dietician	37 (9/24)	2.3	1-4
Psychiatrist	0	-	-
Psychologist	8 (2/24)	2	-
Counsellor	8 (2/24)	1.5	1-2
Social worker	37 (9/24)	1.8	1-3
Care assistant/home care nurse	71 (17/24)	-	-
Wheelchair clinic	79 (19/24)	1.6	1-7
Shoe clinic	4 (1/24)	2	-
Hearing aid clinic	12 (3/24)	2	-
Hydrotherapy	4 (1/24)	52	-

Table 100. Total costs for 24 children living at home over previous 12 months (Noyes, 2006)

Cost category	Sum £	Range of costs £		Mean cost £	SD £	% of total cost
		Minimum	Maximum			
Equipment						
NHS	154,233	1,894	20,186	6,426	3,723	
Charity/voluntary sector	5,606	0	3,058	234	795	
Parents	6,333	-	-	-	-	
Independent	7,116	-	-	-	-	
Total	**173,288**	**1,894**	**20,186**	**7220**	**4,689**	**6.9**
Hospital services						
In-patient stays	429,918	0	154,700	17,913	35,724	
Out-patient appointments	14,476	0	1,260	603	307	
A&E attendances	600	0	225	25	53	
Total	**444,994**	-	-	**18,541**	-	**17.8**
Ambulances	**11,019**	**0**	**5,000**	**459**	**1,030**	**0.4**
Community health services (NHS)	**60,470**	**72**	**7,353**	**2,520**	**2,219**	**2.4**
Primary care servs	**20,788**	**0**	**3,776**	**866**	**789**	**0.8**
Social services	1,351	0	998	56	200	0.1
Pharmacy	**48,179**	**0**	**10,556**	**2,007**	**2,741**	**1.9**
Disposable eqpmt & supplies	195,183	1,000	15,876	8,133	5,216	7.8
Education	**171,424**	**0**	**18,050**	**7,143**	**6,465**	**6.8**
Nursing/ personal/ respite care						
NHS	1,141,477	0	158,369	47,562	59,995	
Social services	19,737	0	13,871	822	2,859	
Charity/voluntary sector	35,416	0	15,347	1,476	3,472	
Independent	181,126	-	-	-	-	
Total	**1,377,756**	**0**	**181,126**	**57,407**	**63,710**	**55.0**
Grand total	**2,504,452**	**10,008**	**331,619**	**104,352**	**84,082**	**99.9**

Table 101. Annual support costs for children living in hospital and at home (Noyes, 2006)

Provider	Those in hospital (n=7) Cost (% of total cost)	Those living at home (n=24) Cost (% of total cost)
NHS	£3,304,777 (97.9)	£2,076,343 (82.9)
Social services	£37,945 (1.1)	£21,088 (0.8)
Education	£26,809 (0.8)	£171,424 (6.8)
Charity/voluntary sector	£0	£41,022 (1.6)
Independent	£0	£188,242 (7.5)
Parents	£6,283 (0.2)	£6,333 (0.3)
Total	£3,375,814 (100.0)	£2,504,452 (99.9)

Index cases with the most expensive support packages employed care teams with a high ratio of trained nurses and/or required readmission to hospital. Providing employed care in the home or in a respite facility cost £1.4m (55 per cent of total costs), an average of £57,400 per child. Total costs of purchasing and servicing equipment were £173,300 (7 per cent of total costs), an average of £7,220; whilst those for disposable equipment and supplies were £195,200 (8 per cent), an average of £8,133 per child.

Economic analysis

The costs analysis in Stutts (1994) showed that there was a decrease in monthly nursing charges when parents received prescribed child care services. Monthly prescribed childcare savings ranged from $178 to $1403 compared to home nursing care. There were no comparisons to hospitalisation, and no assessment of the financial and economic impact on the family of the different models of care.

Field (1993) estimated the costs of care for children in a persistent vegetative state managed at home to be an average of $90,000 per annum. Costs for the least costly alternative institution capable of caring for such children were assessed to be an additional $40,000 per annum. The outcomes for these children were poor, and none in their study had any functional recovery. Because of the poor outcomes, and very high resource utilisation and costs, the study authors stated that resource allocation to these children should be re-assessed, even given the lower cost of home care management.

The Noyes (2006) study compared the costs of hospital versus home care for four ventilator-dependent children discharged during the previous 12 months. Table 102 summarises these findings.

Table 102. Costs of home and hospital care for children discharged in previous 12 months (Noyes, 2006)

Child	Home care costs		Hospital costs	
	Total (£)	Average monthly cost* (£)	Total (£)	Average monthly cost* (£)
A: 3 months hospital/9 months home	26,491	2,943	73,967	24,656
B: 4 months hospital/8 months home	121,995	15,249	139,265	34,815
C: 7 months hospital/5 months home	21,534	4,307	364,533	52,076
D: 1.5 months hospital/10.5 months home	8,200	4,699	74,017	49,345

* Calculated by us.

Noyes (2006) also estimated the total costs of support under seven scenarios, three of which were hospital based and four home based, using appropriate mean costs from the study. Table 103 summarises these and shows that it is not necessarily cheaper for ventilator dependent children to live at home. If most ventilator-dependent children are managed under models A or B, then being managed at home will be less costly. However, if there is a higher ratio of unqualified to qualified staff (the alternative to model B), it would be cheaper for a child to be managed in such a unit than with qualified home care staff.

This study does show ways that costs can be reduced for home management, but also points out that the packages put in place must meet the needs of the child, otherwise they may be re-admitted to expensive hospital care. This study also found that children were not necessarily placed in settings that met their needs, that those in intensive care were not necessarily those with highest needs and, conversely, that children cared for by their parents were not always those with the lowest needs.

6.6.2 Home haemodialysis

Type of study

A single, very small study, was included here (Geary, 2005).[j] Clinical, psychosocial and cost data were collected prospectively on four teenagers in receipt of one model of home nocturnal haemodialysis (HNH), selected according to agreed criteria. Their costs were compared to those of teenagers in receipt of thrice-weekly in-centre care. The four families

[j] Although included here, this study was excluded from the other comparative studies section of the review because of the very small numbers and because the study was a feasibility study only.

agreed to participate in the programme and completed the training requirements. Data was collected over a 12-month period. No children left the programme and none died.

Table 103. Comparison of total costs of 12 months support in different hospital and home care scenarios (Noyes, 2006)

Scenario	Total costs
Model A: 12 months in paediatric intensive care unit	£630,388
Model B: 12 months in high dependency long-term ventilation unit	£301,888
Alternative to model B, high dependency care with lower qualified/unqualified staff ratio	£182,500
Model C: 12 months in children's ward	£155,158
Model D: 12 months 24-hour home care from E-grade nurses, with 7.5 hours per week support from team leader	£239,855
Model E: 12 months 24-hour home care from 50 E-grade nurses and 50 B-grade health care assistants, with 7.5 hours per week support from team leader	£200,515
Model F: 12 months 24-hour home care from B-grade health care assistants, with 7.5 hours per week support from team leader	£161,174
Model G: 12 months parents as unpaid carers	£46,483

Nature of intervention

The objective of the study was to investigate the viability of HNH, which is commonly available for adults, as an alternative to peritoneal dialysis for children. Although the study refers to a 'substantial' nursing commitment associated with HNH, it is not clear from the paper how much of this commitment was related to training for parents before the HNH started and how much to providing care and support in the children's own homes.

Cost data collected for the study of home dialysis

As shown in Tables 104 and 105, programme, patient and training, and treatment costs were collected in some detail. The programme costs included all actual costs of home renovations such as plumbing, water testing, electrical and telephone lines. All elements associated with the six week training programme were itemised and costed. All equipment was itemised and costed including dialysis machines, water softeners, computer hardware, reverse osmosis machines and home centrifuge machines. All of these costs were summed and amortised over one year, apart from equipment, which was amortised over five years. Staff costs were itemised prospectively, with nursing costs calculated on the basis of a nurse to patient ratio of 1:8, summed and expressed as an average across the four patients. No costs were included for physicians or for medication.

Table 104. Type of cost data collected (Geary, 2005)

Type of cost data	Home nocturnal haemodialysis	In-centre haemodialysis
Costs of development	Yes	No
Patient/training costs	Yes	No
Annual cost of treatment	Yes	Yes

Table 105. Average annual costs (Geary, 2005)

Type of cost	Home nocturnal haemodialysis	In-centre haemodialysis
Costs of development	Can$4200	-
Patient/training costs	Can$9000	-
Annual cost of treatment	Can$63670	Can$88,000 Can$76,000 (10 years previously)

Reported costs of care

Despite the obvious detailed build-up of the costs, the individual costs associated with the individual components were not included in the published paper, merely the totals. There are also no details about the component parts of the in-patient comparator.

The authors commented on the significant psychosocial burden placed on the families associated with HNH, but they appeared not to quantify the costs associated with this burden, or any additional costs to the families associated with this form of treatment.

Economic analysis

Geary (2005) reports that psychosocial and clinical outcomes were improved, though not consistently. HNH also appears to be less expensive per patient, representing savings of 27 per cent compared to thrice weekly, in-centre haemodialysis. The cost reduction is associated with the reduction in staffing, although the authors state that that supply costs are more than twice those associated with traditional haemodialysis. These costs comparisons are not shown.

The authors hinted at sensitivity analysis that could be performed, including a reduced nurse to patient ratio, and amortisation of equipment for longer than five years. However, these results were not performed as they believed that their analysis based on the more conservative assumptions were more realistic.

7 Integration and discussion of findings

This chapter integrates the evidence reviewed in the previous four chapters. As we saw, the models of CCTH reviewed were not the same in each chapter, and we also found that they sat together in slightly different ways. Further, the descriptive review of publications about UK CCTH services generated a different patterning of services, while the three 'evaluative' chapters, based on international evidence, were more consistent (see Table 106).

Table 106. Models of CCTH services reviewed in the updated systematic review by type of studies

Model of CCTH	Type of studies reviewed			
	RCTs	Other comparative studies	Health economics	Descriptive
Home care for VLBW/medically fragile/NICU babies	Y	N	Y	N
Home care for diabetes	Y	Y	Y	N
Home care for mental health problems	Y	Y	Y	Y
HaH/admission avoidance/early discharge for acute conditions	Y	Y	Y	Y
Home care for childhood cancer	Y	N	Y	N
Telemedicine	Y	Y	N	N
Technological care at home, including dialysis	N	Y	Y	N
Palliative care	N	Y	N	Y
Generic home care	N	N	N	Y
Condition specific home care	N	N	N	Y
Children's Community Nursing Teams	N	N	N	Y
Ambulatory care	N	N	N	Y
Multiple integrated services	N	N	N	Y

Given this, and the different objectives of the evaluative and descriptive reviews, in what follows we first integrate messages from the RCTs, other

comparative designs and health economics chapters before discussing the material from the descriptive review.

The chapter concludes with a discussion on methodological and interpretive issues of the papers included in the systematic review, and the implications of these issues for the paediatric care closer to home evidence base.

7.1 Integration of evidence on models of home care from RCTs, other comparative designs and health economics analysis

7.1.1 Models of home care for very low birth weight or medically fragile babies

This category includes evidence from the RCT and health economics chapters. The single study in the RCT chapter had low quality scores. While initial length of stay (LOS) was significantly shorter for the early discharge group, there was no evidence about the total length of stay when including hospitalised periods during readmissions. The previous review reported conflicting evidence regarding the impact of this model of care on initial length of stay, and this additional single finding is not enough to lend weight to one particular direction of the evidence. Reflecting evidence from the previous review, this study suggests there is a similar rate of subsequent readmissions and emergency department visits in both groups. The main impact of this model of care on health service use, then, is that it reduces initial LOS.

The two clinical outcomes reported were either equivalent for the two groups (days on oxygen) or better for the early discharge group (weight gain). However, sub-group analysis showed that most of this effect was explained by babies who had been the most premature (gestational age of less than 27 weeks).

The RCT considered costs only for the initial hospital stay and, as would be expected, showed savings for the health service. Two studies of home care for similar babies that were included in the health economics chapter demonstrated similar outcomes in home care alongside savings to the health service, taking into account all aspects of post-hospital care, including the costs of the home care service itself. Two other studies looked at early supported discharge for babies requiring home gavage-feeding or home oxygen. Both reported health cost savings, associated with shorter initial LOS, and equivalent outcomes.

The previous review noted the lack of outcomes relating to the impact on families of these models of care; this remains a neglected area for this intervention. The responsibility of caring for a vulnerable infant with complex health care needs will inevitably affect the carers, both psychologically and financially. More evidence is needed to assess the impact of caring for a medically fragile baby at home and how this may affect the long term care of the child.

7.1.2 Models of home care for children with diabetes

One new RCT and three other studies were identified for this category. The three other studies each assessed different elements of the same service and were included in both the other comparative and health economics sections. It is difficult to invest confidence in these findings, however, given that the trial was reported in a conference abstract only and the three other studies were before and after audits using no formal evaluation methods.

No outcomes for health service use were reported in the trial abstract. The studies of another comparative design showed a reduction in length of stay and hospital admissions after the establishment of the home care team; however, this was reported as a trend and not as part of a formal evaluation. Other possible factors contributing to these trends, for example secular reductions in LOS in all hospital settings, were not accounted for.

Clinical outcomes for this model of care remain contradictory. The trial abstract claimed that there was no difference in metabolic control and insulin dose between the intervention and control group. By contrast, the other studies showed a reduction in HBA_1 after interventions. Again, however, these data were reported as trends, and the differences between start and end points were not tested for statistical significance. Given the strongly conflicting evidence also found in the previous review, the current evidence base for this model of CCTH in terms of **improved** outcomes remains unsure.

The other comparative studies calculated only savings from the reduction in LOS that they argue were a result of the home care service, and claimed that these were greater than the costs of the home care unit. However, these latter costs were not detailed in the relevant publication.

Evidence for this type of model of care is thus limited, and weakened by low quality scores. In the studies included here, the focus was mostly clinical, with no attention given to the impact on families and children. In addition, the age range of the samples in the other comparative design studies was wide ranging (0-19 years) with no analysis of trends by age. This is an important issue, given that self-care is typically a large component of these care models, and responsibility for self-care is associated with age (Anderson *et al*., 1990).

7.1.3 Models of home care for children and adolescents with mental health problems

Integration of findings for this model of care is difficult due to the lack of information about the models of care and the variation in health conditions of the children sampled. Two trials and three other comparative studies were included, plus an additional health economics study, covering a range of home based interventions. The quality scores for the trials were low, and the quality of the evidence for the other studies was also poor. This was often because of the underreporting of, or weak, methods.

One trial and one other comparative study reporting clinical evidence showed outcomes such as symptom improvement were often not significantly different between groups, suggesting that the home-based model of care was no less effective than hospital-based care. Additional clinical outcomes in the other study showed that while there was no difference between groups, the intervention group showed significantly greater improvement at follow-up compared to baseline scores.

Impact on family, education and social and mental functioning were reported in both the trials and the other comparative studies of mental health care. Outcomes relating to impact on social functioning and education mostly showed no difference between groups, indicating that the model of care was comparable in this respect. Impact on family related to family issues, where there was improvement for both groups. Evidence for family impact in the previous review had examined specific issues relating to the location of the intervention, such as being distracted by neighbours, and availability of resources. These issues were not addressed in the studies reviewed here. Given that these interventions take place in the home and can involve substantial involvement of family members, as well as delivery of treatment at home, issues of an unsuitable environment with distractions may affect both the success of the intervention and the family's and young person's preferences.

The single included health economics study reported costs based on unexplained assumptions about LOS in hospital as compared to home care.

7.1.4 Models of technological care at home

For this category, the evidence can be updated for the following technological interventions: home oxygen therapy (HOT), home intravenous therapies (IV), central venous catheters (CVCs), home nocturnal haemodialysis (HNH), home traction and home parenteral nutrition (HPN). Additional evidence is reviewed for home traction.

No RCTs were identified for this category and so only evidence from other comparative and health economics studies could be reviewed. Across these papers, most commonly reported outcomes were costs to health service. Clinical outcomes, by contrast, were reported in only two studies.

Home IV, CVC & HPN

The evidence for these three interventions is discussed together here, as one included study examined a care package including all three. There was mixed evidence regarding health service use for these interventions, with two studies showing shorter hospital stay for the intervention group (although only in one case was this significant), while other evidence showed the intervention group made more clinic visits but received fewer physician visits. Only two studies reported clinical outcomes; this is surprising, given the technological nature of the care. Overall, there was no strong evidence to suggest that the home-based interventions were less clinically effective than routine care.

Only two studies in this sub-section reported costs, both of which included home IV and other medical care. Both showed significantly lower costs compared to routine care but no clinical outcomes were reported.

Only three of the included studies relate to home-based delivery of these interventions and thus there is insufficient evidence to come to a firm conclusion. The existing evidence base is also weakened by weaker methods – two studies used existing patient data rather than formally evaluating recruited participants. Further evidence is needed to establish not only the demands of these interventions on health service resources, but also their clinical effectiveness. The technological complexity of this type of care will also inevitably affect families and carers, and more evidence on this is also needed.

Home oxygen therapy for children

Only costing studies were identified for this intervention in the previous review. In the updated review only one study, which studied infants with chronic lung disease using another comparative design was included. The sample size was very small.

Quality of life and impact on family outcomes were reported, and findings suggested that this type of home care had a negative impact on carers. Given the very small sample size more reliable evidence is needed to support this finding.

Home nocturnal haemodialysis

One study that examined HNH was included in the health economics chapter. This was a feasibility study that used only four participants and made preliminary observations in improvements to physical and mental functioning, and the impact on school attendance. Despite an apparently detailed work up of costs for this study, little detail was given in the published paper; the authors nevertheless claim savings of 27 per cent compared to hospital-based haemodialysis.

Home traction

Two studies were included here – one in the other comparative section and one in the health economics section. The first showed no difference in costs to health services; however, it was based on a small sample, and may have been underpowered to detect a difference. It did offer some evidence regarding impact on families, and suggested that this was negative. By contrast, the study included in the health economics section involved a detailed work-up of costs, including those falling to families. Based on a 'natural experiment', the study compared different care models in three different hospitals and showed substantial savings for traction at home, compared to hospital.

7.1.5 Home chemotherapy

We included one RCT of home chemotherapy, which was also reviewed in the health economics chapter. There was a quality of life gain for children

associated with the home chemotherapy regime, while the costs of care after treatment associated with home care and hospital care were equivalent.

7.1.6 Models of home care for acute physical conditions and models of admission avoidance in the home

The findings from these two categories are combined here, as the models of care are similar in operation and objectives. Three RCTs and one other comparative study were included, two of which studied interventions addressing numerous acute conditions, and two of which were (acute) condition specific.

Despite the fact that health service use outcomes were reported in all studies, the overall evidence is unclear. One RCT suggested that more days of care and a higher number of readmissions might result from the intervention. A comparative study, by contrast, suggested a decrease in length of stay after the intervention, despite the fact that readmissions increased for children being admitted on one occasion. Evidence from the comparative study also showed mixed patterns concerning total number of admissions post intervention; for some conditions and age groups the number of admissions increased, whereas for others they decreased. The lack of strong evidence for health service use makes it difficult to conclude anything with certainty about the impact of the intervention in this respect.

There was also limited reporting of clinical effectiveness across the trials, and no reporting of this outcome in the other comparative study. For the condition specific study of buckle fractures, the intervention was no less clinically effective than routine care.

One RCT and the other comparative study suggest that home care costs more, however neither study was able to take into account full service capacity and longer term savings that might accrue from disinvestment in hospital care.

Overall, family costs were lower in home care, however one trial suggested that delay in admission to home care might result in loss of work time for parents. The other comparative study also suggested there may be additional costs associated with parents requiring extra help whilst caring for their child at home, however these costs were not explored further in the study. These two additional factors (delayed admission and requiring extra help) may result in increased costs for families using these interventions, and further exploration of these issues is needed.

The findings generally showed that the interventions had little negative impact on children and families, although one RCT did show that parents using the CCTH service did spend more time on care activities, such as administering medication, and less time on play activities. It is difficult to interpret this as either completely positive or negative. Some parents may not wish to spend more time on care activities, whilst others may prefer this type of involvement. In the same RCT, however, many parents, including those in the control group, did report a preference for CCTH.

7.1.7 Models of admission avoidance in hospital settings

No RCTs and six other comparative studies were included here, all looking at ambulatory care models. Much of the evidence reported concerned health service admission. While reductions in LOS were observed in most studies, only two studies reported the statistical significance of these changes. At best, this evidence provides some indication that these ambulatory models of care go some way to reducing inpatient admission, however this should be considered a preliminary finding that requires further support. There was limited reporting of other outcomes and thus no conclusions can be drawn about the clinical effectiveness, cost and impact of these models of care.

7.1.8 Early discharge from hospital

Two other comparative studies were identified for this category, both related to models of care to support discharging children with complex or long-term needs from hospital. Outcomes were reported for clinical, health service use and costs. The evidence for clinical effectiveness suggested that CCTH was no less effective than routine care, while limited costing data favoured CCTH. These studies were not, however, included in the health economics chapter.

7.1.9 Home based alternatives to clinic based care

This category was not covered in the previous review, and only two RCTs were identified here. Few outcomes were reported. Overall, clinical outcomes suggest that while the intervention group showed improvement over time, this was not significantly different from routine care. Physical and mental functioning outcomes were better for the intervention group in the one study that reported them.

7.1.10 Models of palliative care closer to home

No trials or health economics studies were identified for this category, and so the evidence reviewed is from three studies using other comparative designs.

Clinical outcomes were not reported, and the focus was mainly on satisfaction with services. However, the methods used to assess satisfaction and reporting of findings were weak. One study reported a higher proportion of children dying at home after introduction of the home care service and a concomitant reduced number of days spent in hospital. However, the comparator for the last outcome was not clear

7.1.11 Telemedicine

At the time of the previous review, telemedicine seemed to be an emerging technology in the literature, however the evidence identified for our updated review is not robust enough to reveal whether it offers any real benefits to children and their families.

One RCT and four other comparative studies were included.

As the primary objective of telemedicine is to reduce hospital visits and admission, it is disappointing that only one of the five studies included this as an outcome. This single study suggested that telemedicine might reduce unscheduled hospital visits for children dependent on home respiratory technology. However, this was a very small study and, on its own, this finding carries little weight.

Similarly, clinical outcomes were reported in only one study, where telemedicine was reported to be associated with improved outcomes for asthma in a small before and after study. Again, this evidence should be taken as preliminary until larger, controlled studies have been undertaken.

Although outcomes relating to quality of life, satisfaction and impact on the family were reported, the data and measurement were in some cases not reported clearly. As a result, there is no strong evidence to describe the impact of telemedicine on children and their families. No studies including information related to the costs and health economics of telemedicine were identified.

7.2 The descriptive studies of care close to home in the UK

The analysis of the descriptive studies of CCTH in the UK confirms the three 'dimensions' of services identified in earlier work (e.g. Tatman and Woodroffe, 1993; While and Dyson, 2000; Parker *et al*., 2002). Firstly, models can be distinguished as primarily home based or hospital based. Secondly, services can be either generic or condition specific. The nature of their staffing appears to be reflected in this distinction. Thirdly, care can be short term or long term (dictated by whether the service provides acute care or not). The second and third dimensions relate primarily to models of home based care. Thus, ambulatory models of care provided exclusively in hospital settings vary less in terms of their service delivery and organisational characteristics.

The objectives of CCTH suggest that primary care will play a key role, particularly when that care is provided in the community. Despite this, very few of the accounts identified for the descriptive review discuss the implications for primary care. Some, though, do describe the importance of cultivating relationships with and building ties into primary care. In some cases, there was an indication that primary care staff felt their workload might increase with the implementation of CCTH services. Other services also highlighted the involvement of the GP, but with little discussion of how this was done and to what effect.

Although these accounts offer some insight into CCTH services, information about service delivery and organisational features was not available in most cases; thus a comprehensive understanding of this type of care is not possible. Given the variability in the types of services that provide CCTH for ill children and young people, comprehensive work is needed to explore

patterns of service provision, and how these services are organised and delivered.

7.3 Limitations of the review

7.3.1 Methodological and interpretive issues

Although there has been further research about models of home care for children and young people who are ill since the original review (Parker *et al*., 2002), the international evidence overall remains weak.

Perhaps the most substantial weakness in the international literature is the lack of robust comparison. Other comparative designs predominate and these are often of poor quality, without any type of control group, statistical testing, or sample sizes that would provide the power to detect differences. Even the RCTs we included were often weak; this was particularly disappointing given that all were carried out after publication of the CONSORT guidelines.

Sufficiently large samples are, of course, hard to come by in this type of research, given that the population of children ill enough to warrant formal clinical intervention is relatively small. In addition, recruitment of families to randomised trials can be difficult because of issues regarding apparent withholding of treatment. There is a further danger where studies use very wide exclusion criteria and thereby produce samples that are not representative of the population of interest. This is a particular issue where families do not use English as a first language or where their household circumstances militate against delivering CCTH services, both found widely as exclusion criteria in included studies.

While small sample sizes will always make evaluation of services for ill children challenging, there seems no reason why other aspects of study design, conduct and reporting should not be of high quality

7.3.2 Neglected issues

It is clear from the included studies that certain key issues are missing. Ethnicity has been largely ignored, as have the potential needs of ethnically or culturally diverse groups, such as those requiring interpreters. As a result, there was no insight into how services might work in different cultural contexts. Discussion of the impact of socio-economic deprivation among users, and how it might mediate the impact of CCTH services was also notable by its absence. Delivery of CCTH services in the home influences the working lives of families caring for the child. Where family income is low, the impact of home care on employment arrangements needs to be addressed more adequately. While some studies did address financial costs for families, many did not. Issues of access were also ignored in most studies, so it is not known how well these services may work for populations who are hard to reach (e.g. in rural areas) or who have access to poor transport links. In some studies, individuals were excluded if they

resided too far from the base site, thus excluding the possibility of addressing these research questions.

7.3.3 The interventions

Another key limitation of these studies was that they often lacked detail about the operational aspects of the CCTH service being evaluated. When service developers draw upon evidence in decision-making, they also need to understand how the evaluated service operates. Evidence of effectiveness or its lack is redundant if we do not know exactly what is being evaluated. There is also very little description about how CCTH services were developed, in response to what need, and on the basis of what evidence, if any. This makes it difficult to understand the wider context of the service and the justification of the outcome variables chosen for evaluation.

7.3.4 Scope of the evidence

The previous review highlighted the lack of outcomes relating to the impact of services on children and their families. Some progress has been made here, as some included studies did address these issues. However, a major limitation remains in the use of measures that are either not clearly explained, or unsupported by evidence about their reliability and validity. The reliable and tested SF-36 was used for families and carers only rarely; if used more consistently across studies this would allow more opportunity for synthesis.

While some studies looked at the impact on the child, this was done in a very limited way. For children who receive long-term care in the home and do not have access to support networks that may be available in hospital settings, there may be consequences for the child's social development. More evidence is needed about the impact of home care on the child's social development, including coping and resilience, ability to develop social support networks and ability to develop age appropriate social relationships. When seeking views about the service (as opposed to measuring a potential impact) often only the views of parents were sought. The views of children are thus still under-represented in studies of CCTH, which is disappointing given the emphasis current UK policy places on involving young people in service development (Sloper and Lightfoot, 2003; Lightfoot and Sloper, 2003). More effort should be invested in seeking the views of children about their care, rather than focusing solely on parents' perspectives.

Health service use was a popular outcome variable in these studies, which suggests that reducing demand on health services was a key objective of the interventions. The focus however was often on reducing admissions and length of hospital stay, and very few studies assessed the impact on primary care and community care activity. As many of these services move care from the hospital into the community, care will inevitably be a joint endeavour between primary and secondary practices. Research thus needs to explore how these models of care affect primary care resources. Also

under-researched are issues relating to the impact of home care on social care practices; children with complex health care needs will experience aspects of social care, particularly for older children who are experiencing service transitions. None of the studies included here explored the implications of the intervention for social care, something that needs to be addressed in future research.

While 'satisfaction' is measured in some studies, it would perhaps be more appropriate to explore this using qualitative methods, given that it is a subjective concept. Some studies used qualitative methods to gather data on satisfaction and parents' views, however in several cases the studies did not fully explore the user's experience and as a result only a superficial picture was provided.

7.4 Implications for health care

While the evidence base related to CCTH has not grown substantially since the previous review, the research that we included in this updated review has added weight to the conclusion that models of CCTH do not deliver poorer clinical outcomes for children; neither, overall, do they impose a greater burden on families. Indeed, in some cases, there is evidence of reduced burden and costs for families. Alongside this, there is growing evidence, albeit based on rather weaker evidence, that CCTH may well reduce costs for health services. This appears to be particularly the case for children with the most complex and long-term needs, but cost reductions are also influenced by skill mix and the ability to deliver cost reductions in other parts of the local health economy. Descriptive accounts of CCTH in the UK are disappointingly vague on the service delivery and organisational features of the services, giving little guide to best practice.

7.5 Recommendations for future research

Both the number and quality of RCTs identified for this review that have been published since the earlier one (Parker *et al*., 2002) nor the number of other comparative studies that do not allow robust messages to emerge, suggest a rapidly developing evidence base in this field. At the same time, however, descriptive studies of UK-based services continue to be published at a fair rate, suggesting the growth of relatively under-evaluated models of care. However, as acknowledged earlier in this chapter, evaluative research in the field of acute paediatric care poses challenges, particularly in generating sample sizes large enough to detect statistical difference.

Given the above, the most important research recommendation from this review is that when new models of CCTH are implemented, they should, at the very least, be accompanied by robust before and after audits of activity, outcomes and, crucially, costs. Having even this basic level of information would transform the evidence base on models of care closer to home and the scope for national evaluation.

Our second recommendation is that thought needs to be given to how the service delivery and organisational features of evaluated models of care are best described in the literature. While guidelines for conducting and reporting RCTs exist, there is no comparable guidance for what to describe about the models of care that are being evaluated, or how to do so. It is not helpful for health service managers if 'effective' models of care are reported in the evaluative literature with little or no information about how these models were established, their key organisational features, and the contexts in which they operate.

Beyond these generic recommendations, the review has highlighted a number of specific research issues that future research could usefully address. We list these in order of importance.

1. Research that examines the impact on children and young people of receiving CCTH over the long term, with a particular focus on their social networks, social development and capacity for self-care.
2. Research that examines the views of children and young people about the development of CCTH services.
3. Research that examines in detail the impact of CCTH services on primary and community health service activity, with a particular focus on costs.
4. Qualitative research on issues of satisfaction with CCTH services.

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Appendix 1 Databases and search strategies

Databases searched

MEDLINE

MEDLINE in process

British Nursing Index (BNI)

Cumulative Index to Nursing & Allied Health Literature (CINAHL)

Health Management Information Consortium (HMIC)

The Cochrane Library

ASSIA

Social Services Abstracts

PsycINFO

Science Citation Index (Expanded)

Social Science Citation Index

EMBASE

ISI Proceedings – Science and Technology

Clinical Trials.gov

Social Care Online

DoH Point

CenterWatch

Dissertation Abstracts

Index to Theses

National Research Register

Current Controlled Trials

MEDLINE (Ovid Online –www.ovid.com/)

1950 to April Week 2 2007

Searched on 23/4/2007

Retrieved 5584 hits

and

MEDLINE in process (Ovid Online – www.ovid.com/)

April 20 2007

Searched on 23/4/2007

Retrieved 72 hits

Search strategy

1. exp Home Care Services/
2. Aftercare/
3. Group Homes/
4. Nursing, Private Duty/
5. exp Program Evaluation/
6. "Outcome and Process Assessment (Health Care)"/
7. "Process Assessment (Health Care)"/
8. "Continuity of Patient Care"/
9. Comprehensive Health Care/
10. Patient Care Team/
11. Intervention Studies/
12. exp Patient care planning/
13. exp Self care/
14. Models, nursing/
15. or/4-14
16. home.tw.
17. 15 and 16
18. domiciliary.tw.
19. home based.tw.
20. homebased.tw.
21. (social support and home$).tw.
22. (homecare or medical home).tw.
23. (home and package$).tw.
24. (outreach and home).tw.
25. (alternative setting$ and home).tw.
26. technolog$ depend$.tw.
27. home test$.tw.
28. home visit$.tw.
29. home manag$.tw.
30. homecare.tw.
31. home care.tw.
32. home therap$.tw.
33. model$ home$.tw.
34. home program$.tw.
35. home monitor$.tw.
36. or/18-35
37. 1 or 2 or 3 or 17 or 36
38. exp Child/
39. exp Child health services/
40. Pediatrics/

41. Aid to families with dependent children/
42. Child welfare/
43. Child advocacy/
44. exp Child care/
45. Pediatric nursing/
46. or/38-45
47. teenage$.tw.
48. schoolchild$.tw.
49. pupil$.tw.
50. school age$.tw.
51. preschool.tw.
52. pre school.tw.
53. child$.tw.
54. infant$.tw.
55. babies.tw.
56. baby.tw.
57. adolescent$.tw.
58. or/47-57
59. 58 or 46
60. 37 and 59
61. exp Adult/ not (exp Adult/ and exp Child/)
62. 60 not 61
63. 62
64. limit 63 to yr="1990 - 2007"

EMBASE (Ovid Online – www.ovid.com/)

1980 to 2007 Week 18

Searched on 4/5/2007

Retrieved 4207 hits

Search strategy

1. exp Home Care/
2. Aftercare/
3. Residential Home/
4. exp Nursing Care/
5. Health Care Quality/
6. Treatment Outcome/
7. Nursing Evaluation Research/
8. Total Patient Care Nursing/
9. Team Nursing/
10. Intervention Study/
11. Patient care planning/
12. exp Self care/

13. Nursing Assessment/
14. or/4-13
15. home.tw.
16. 14 and 15
17. domiciliary.tw.
18. home based.tw.
19. homebased.tw.
20. (social support and home$).tw.
21. (homecare or medical home).tw.
22. (home and package$).tw.
23. (outreach and home).tw.
24. (alternative setting$ and home).tw.
25. technolog$ depend$.tw.
26. home test$.tw.
27. home visit$.tw.
28. home manag$.tw.
29. homecare.tw.
30. home care.tw.
31. home therap$.tw.
32. model$ home$.tw.
33. home program$.tw.
34. home monitor$.tw.
35. or/17-34
36. 1 or 2 or 3 or 16 or 35
37. exp Child/
38. exp Child health care/
39. Pediatrics/
40. Social Security/
41. Child welfare/
42. Child advocacy/
43. exp Child care/
44. exp Pediatric nursing/
45. or/37-44
46. teenage$.tw.
47. schoolchild$.tw.
48. pupil$.tw.
49. school age$.tw.
50. preschool.tw.
51. pre school.tw.
52. child$.tw.
53. infant$.tw.
54. babies.tw.
55. baby.tw.

56. adolescent$.tw.
57. or/46-56
58. 57 or 45
59. 36 and 58
60. exp Adult/ not (Adult/ and exp Child/)
61. 59 not 60
62. 61
63. limit 62 to yr="1990 - 2007"

British Nursing Index (BNI) (Ovid Online – www.ovid.com/)

1994 to March 2007

Searched on 24/4/2007

Retrieved 211 hits

Search strategy

1. Home Care Services/
2. Nursing Care/
3. Quality Assurance/
4. "Continuity of Care"/
5. "Care Plans and Planning"/
6. Self care/
7. "models and theories"/
8. or/2-7
9. home.tw.
10. 8 and 9
11. domiciliary.tw.
12. home based.tw.
13. homebased.tw.
14. (social support and home$).tw.
15. (homecare or medical home).tw.
16. (home and package$).tw.
17. (outreach and home).tw.
18. (alternative setting$ and home).tw.
19. technolog$ depend$.tw.
20. home test$.tw.
21. home visit$.tw.
22. home manag$.tw.
23. homecare.tw.
24. home care.tw.
25. home therap$.tw.
26. model$ home$.tw.
27. home program$.tw.

28. home monitor$.tw.
29. or/11-28
30. 1 or 10 or 29
31. Children/
32. exp Children Services/
33. Children Rights/
34. Paediatric Nursing/
35. Paediatric Community Nursing/
36. or/31-35
37. teenage$.tw.
38. schoolchild$.tw.
39. pupil$.tw.
40. school age$.tw.
41. preschool.tw.
42. pre school.tw.
43. child$.tw.
44. infant$.tw.
45. babies.tw.
46. baby.tw.
47. adolescent$.tw.
48. or/37-47
49. 36 or 48
50. 30 and 49

CINAHL - Cumulative Index to Nursing & Allied Health Literature (Ovid Online – www.ovid.com/)

1982 to April Week 3 2007

Searched on 25/4/2007

Retrieved 3735 hits

Search strategy

1. exp home health care/
2. Aftercare/
3. Residential Care/
4. Home Nursing, Professional/
5. Program Evaluation/
6. Outcome Assessment/
7. "Process Assessment (Health Care)"/
8. "Continuity of Patient Care"/
9. Private duty nursing/
10. multidisciplinary care team/
11. Intervention Trials/
12. exp Patient care plans/

13. exp Self care/
14. or/4-13
15. home.tw.
16. 14 and 15
17. domiciliary.tw.
18. home based.tw.
19. homebased.tw.
20. (social support and home$).tw.
21. (homecare or medical home).tw.
22. (home and package$).tw.
23. (outreach and home).tw.
24. (alternative setting$ and home).tw.
25. technolog$ depend$.tw.
26. home test$.tw.
27. home visit$.tw.
28. home manag$.tw.
29. homecare.tw.
30. home care.tw.
31. home therap$.tw.
32. model$ home$.tw.
33. home program$.tw.
34. home monitor$.tw.
35. or/17-34
36. 1 or 2 or 3 or 16 or 35
37. exp Child/
38. exp Child health services/
39. Pediatrics/
40. maternal-child welfare/
41. Child welfare/
42. Child advocacy/
43. exp Child care/
44. Pediatric nursing/
45. or/37-44
46. teenage$.tw.
47. schoolchild$.tw.
48. pupil$.tw.
49. school age$.tw.
50. preschool.tw.
51. pre school.tw.
52. child$.tw.
53. infant$.tw.
54. babies.tw.
55. baby.tw.

56. adolescent$.tw.
57. or/46-56
58. 57 or 45
59. 36 and 58
60. exp Adult/ not (exp Adult/ and exp Child/)
61. 59 not 60
62. 61
63. limit 62 to yr="1990 - 2007"

HMIC (Ovid Online – www.ovid.com/)

March 2007

Searched on 25/4/2007

Retrieved 394 hits

Search strategy

1. exp Home Care Services/
2. Aftercare/ or after care services/
3. exp Group Homes/
4. health service evaluation/
5. outcome measurement/
6. process analysis/
7. Continuity of Patient Care/
8. health care teams/
9. individualised care plans/
10. exp Self care/
11. nursing models/
12. or/4-11
13. home.tw.
14. 12 and 13
15. domiciliary.tw.
16. home based.tw.
17. homebased.tw.
18. (social support and home$).tw.
19. (homecare or medical home).tw.
20. (home and package$).tw.
21. (outreach and home).tw.
22. (alternative setting$ and home).tw.
23. technolog$ depend$.tw.
24. home test$.tw.
25. home visit$.tw.
26. home manag$.tw.
27. homecare.tw.
28. home care.tw.

29. home therap$.tw.
30. model$ home$.tw.
31. home program$.tw.
32. home monitor$.tw.
33. or/15-32
34. 1 or 2 or 3 or 12 or 33
35. exp Children/
36. Childrens health services/
37. Paediatrics/
38. Child welfare/
39. Child advocacy/
40. exp Child care/
41. Paediatric care/
42. or/35-41
43. teenage$.tw.
44. schoolchild$.tw.
45. pupil$.tw.
46. school age$.tw.
47. preschool.tw.
48. pre school.tw.
49. child$.tw.
50. infant$.tw.
51. babies.tw.
52. baby.tw.
53. adolescent$.tw.
54. or/43-53
55. 42 or 54
56. 34 and 55
57. exp Adults/ not (exp Adults/ and exp Children/)
58. 56 not 57
59. 58
60. limit 59 to yr="1990 - 2007"

PsychINFO (Ovid Online – www.ovid.com/)

1985 to April Week 1 2007

Searched on 25/4/2007

Retrieved 2764 hits

Search strategy

1. Aftercare/
2. Group Homes/
3. Home Care Personnel/
4. Program Evaluation/

5. Continuum of Care/
6. Interdisciplinary Treatment Approach/
7. Treatment Planning/
8. exp child Self care/
9. or/4-8
10. home.tw.
11. 9 and 10
12. domiciliary.tw.
13. home based.tw.
14. homebased.tw.
15. (social support and home$).tw.
16. (homecare or medical home).tw.
17. (home and package$).tw.
18. (outreach and home).tw.
19. (alternative setting$ and home).tw.
20. technolog$ depend$.tw.
21. home test$.tw.
22. home visit$.tw.
23. home manag$.tw.
24. homecare.tw.
25. home care.tw.
26. home therap$.tw.
27. model$ home$.tw.
28. home program$.tw.
29. home monitor$.tw.
30. or/12-29
31. 1 or 2 or 3 or 11 or 30
32. Pediatrics/
33. Child welfare/
34. Child care/
35. or/32-34
36. teenage$.tw.
37. schoolchild$.tw.
38. pupil$.tw.
39. school age$.tw.
40. preschool.tw.
41. pre school.tw.
42. child$.tw.
43. infant$.tw.
44. babies.tw.
45. baby.tw.
46. adolescent$.tw.
47. or/36-46
48. 35 or 47
49. 31 and 48

50. 49
51. limit 50 to yr="1990 - 2007"

DARE – Database of Abstracts of Reviews of Effects, HTA (Health Technology Assessment Database, NHSEED (NHS Economic Evaluation Database) CENTRAL (The Cochrane Library – www.thecochranelibrary.com/)

Searched on 25/4/2007

Retrieved 62 hits from DARE, 12 hits from HTA and 188 hits from NHSEED, 981 hits from CENTRAL

Search strategy

N.b. – the MeSH index term for CHILD did not work on this issue of The Cochrane Library.

Text words were searched in all fields

#1	MeSH descriptor Home Care Services explode all trees
#2	MeSH descriptor Aftercare, this term only
#3	MeSH descriptor Group Homes, this term only
#4	MeSH descriptor Nursing, Private Duty, this term only
#5	MeSH descriptor Program Evaluation explode all trees
#6	MeSH descriptor Outcome and Process Assessment (Health Care), this term only
#7	MeSH descriptor Process Assessment (Health Care), this term only
#8	MeSH descriptor Continuity of Patient Care, this term only
#9	MeSH descriptor Comprehensive Health Care, this term only
#10	MeSH descriptor Patient Care Team, this term only
#11	MeSH descriptor Intervention Studies, this term only
#12	MeSH descriptor Patient Care Planning explode all trees
#13	MeSH descriptor Self Care explode all trees
#14	MeSH descriptor Models, Nursing, this term only
#15	(#4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14)
#16	home
#17	(#15 AND #16)
#18	domiciliary
#19	"home based"
#20	homebased
#21	"social support" and home$
#22	homecare or "medical home"
#23	(home and package*)
#24	(outreach and home)
#25	(alternative next setting*) and home
#26	(technolog* next depend*)

#27 (home next test*)
#28 (home next visit*)
#29 (home next manag*)
#30 (homecare)
#31 "home care"
#32 "home next therap*"
#33 (model* next home*)
#34 (home next program*)
#35 (home next monitor*)
#36 (#18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35)
#37 (#1 OR #2 OR #3 OR #17 OR #36)
#38 MeSH descriptor Child explode all trees
#39 MeSH descriptor Child Health Services explode all trees
#40 MeSH descriptor Pediatrics, this term only
#41 MeSH descriptor Aid to Families with Dependent Children, this term only
#42 MeSH descriptor Child Welfare, this term only
#43 MeSH descriptor Child Advocacy, this term only
#44 MeSH descriptor Child Care explode all trees
#45 MeSH descriptor Pediatric Nursing, this term only
#46 (#38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45)
#47 (teenage*)
#48 (schoolchild*)
#49 (pupil*)
#50 (school next age*)
#51 (preschool)
#52 "pre school"
#53 (child*)
#54 (infant*)
#55 (babies)
#56 (baby)
#57 (adolescent*)
#58 (#47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57)
#59 (#58 OR #46)
#60 (#37 AND #59), from 1990 to 2007

Cochrane Database of Systematic Reviews (The Cochrane Library – www.thecochranelibrary.com/)

Searched on 25/4/2007

Retrieved 21 hits

Search strategy

N.b. – the MeSH index term for CHILD did not work on this issue of The Cochrane Library.

#1	MeSH descriptor Home Care Services explode all trees
#2	MeSH descriptor Aftercare, this term only
#3	MeSH descriptor Group Homes, this term only
#4	MeSH descriptor Nursing, Private Duty, this term only
#5	MeSH descriptor Program Evaluation explode all trees
#6	MeSH descriptor Outcome and Process Assessment (Health Care), this term only
#7	MeSH descriptor Process Assessment (Health Care), this term only
#8	MeSH descriptor Continuity of Patient Care, this term only
#9	MeSH descriptor Comprehensive Health Care, this term only
#10	MeSH descriptor Patient Care Team, this term only
#11	MeSH descriptor Intervention Studies, this term only
#12	MeSH descriptor Patient Care Planning explode all trees
#13	MeSH descriptor Self Care explode all trees
#14	MeSH descriptor Models, Nursing, this term only
#15	(#4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14)
#16	home:ti,ab
#17	(#15 AND #16)
#18	domiciliary:ti,ab
#19	"home based":ti,ab
#20	homebased:ti,ab
#21	"social support" and home$:ti,ab
#22	homecare or "medical home":ti,ab
#23	(home and package*):ti,ab
#24	(outreach and home):ti,ab
#25	(alternative next setting*):ti,ab and home:ti,ab
#26	(technolog* next depend*):ti,ab
#27	(home next test*):ti,ab
#28	(home next visit*):ti,ab
#29	(home next manag*):ti,ab
#30	(homecare):ti,ab
#31	"home care":ti,ab
#32	home next therap*:ti,ab
#33	(model* next home*):ti,ab
#34	(home next program*):ti,ab
#35	(home next monitor*):ti,ab
#36	(#18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35)
#37	(#1 OR #2 OR #3 OR #17 OR #36)

#38 MeSH descriptor Child explode all trees
#39 MeSH descriptor Child Health Services explode all trees
#40 MeSH descriptor Pediatrics, this term only
#41 MeSH descriptor Aid to Families with Dependent Children, this term only
#42 MeSH descriptor Child Welfare, this term only
#43 MeSH descriptor Child Advocacy, this term only
#44 MeSH descriptor Child Care explode all trees
#45 MeSH descriptor Pediatric Nursing, this term only
#46 (#38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45)
#47 (teenage*):ti,ab
#48 schoolchild*:ti,ab
#49 (pupil*):ti,ab
#50 (school next age*):ti,ab
#51 (preschool):ti,ab
#52 "pre school"
#53 (child*):ti,ab
#54 (infant*):ti,ab
#55 (babies):ti,ab
#56 (baby):ti,ab
#57 (adolescent*):ti,ab
#58 (#47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57)
#59 (#58 OR #46)
#60 (#37 AND #59), from 1990 to 2007

Science Citation Index Expanded(SCI) (Web Of Knowledge – http://wos.mimas.ac.uk/)

(limited to)1990-2007

Searched on 26/4/2007

Retrieved 1,688 hits

Search strategy

All lines limited as follows:
DocType=All document types; Language=All languages; Database=SCI;
Timespan=1990-2007

#1 TS=(domiciliary or "home based" or homebased or ("social support" and home*) or homecare or "medical home" or (home and package*))

#2 TS=((outreach and home*) or ("alternative setting*" and home*) or "technolog* depend*" or "home test*" or "home visit*" or "home manag*")

#3 TS=(homecare or "home care" or "home therap*" or "model* home*" or "home program*" or "home monitor*")

#4 #3 OR #2 OR #1

#5 TS=(Paediatric* or Pediatric* or teenage* or schoolchild* or pupil* or "school age*")

#6 TS=(Preschool or "pre school" or child* or infant* or babies or baby or adolescent*)

#7 #6 OR #5

#8 #7 AND #4

#9 TS=(health* or illness* or illhealth or therap* or treat* or disabilit* or sick* or medical or medicine*)

#10 #9 AND #8

Social Science Citation Index (SSCI) (Web Of Knowledge – http://wos.mimas.ac.uk/)

(limited to)1990-2007

Searched on 26/4/2007

Retrieved 1560 hits

Search strategy

All lines limited as follows:
DocType=All document types; Language=All languages; Database=SSCI; Timespan=1990-2007

#1 TS=(domiciliary or "home based" or homebased or ("social support" and home*) or homecare or "medical home" or (home and package*))

#2 TS=((outreach and home*) or ("alternative setting*" and home*) or "technolog* depend*" or "home test*" or "home visit*" or "home manag*")

#3 TS=(homecare or "home care" or "home therap*" or "model* home*" or "home program*" or "home monitor*")

#4 #3 OR #2 OR #1

#5 TS=(Paediatric* or Pediatric* or teenage* or schoolchild* or pupil* or "school age*")

#6 TS=(Preschool or "pre school" or child* or infant* or babies or baby or adolescent*)

#7 #6 OR #5

#8 #7 AND #4

#9 TS=(health* or illness* or illhealth or therap* or treat* or disabilit* or sick* or medical or medicine*)

#10 #9 AND #8

ASSIA (CSA Illumina – http://ca2.csa.com/)

1987 to 2007

Searched on 27/4/2006

Retrieved 396 hits

and

Social Services Abstracts (CSA Illumina – http://ca2.csa.com/)

1979 to 2006

Searched on 27/4/2006

Retrieved 427 hits

(((KW=(Paediatric* or Pediatric* or teenage*) or KW=(schoolchild* or pupil* or (school age*)) or KW=(preschool* or (pre school*) or child*)) or (KW=(infant* or babies or baby) or KW=adolescent*)) and ((KW=((home health care) or (long term home care) or (group homes)) or KW=((process evaluation and home) or (continuing care and home) or (care management and home)) or KW=((nursing model* and home) or domiciliary or (home based))) or (KW=(homebased or (social support and home*) or (homecare or medical home)) or KW=((home and package*) or (outreach and home) or (alternative setting* and home)) or KW=((technolog* depend*) or (home test*) or (home visit*))) or (KW=((home manag*) or homecare or (home care)) or KW=((home therap*) or (model* home*) or (home program*)) or KW=(home monitor*)))) and (KW=(health* or illness* or illhealth) or KW=(therap* or treat* or disabilit*) or KW=(sick* or medical or medicine*))

NRR - www.nrr.nhs.uk/

2007: Issue 2

Searched on 30/04/2007

Retrieved 401 hits

Search strategy

#1. HOME CARE SERVICES explode all trees (MeSH)

#2. AFTERCARE single term (MeSH)

#3. GROUP HOMES single term (MeSH)

#4. NURSING PRIVATE DUTY single term (MeSH)
#5. PROGRAM EVALUATION explode all trees (MeSH)
#6. OUTCOME AND PROCESS ASSESSMENT (HEALTH CARE) single term (MeSH)
#7. PROCESS ASSESSMENT (HEALTH CARE) single term (MeSH)
#8. CONTINUITY OF PATIENT CARE single term (MeSH)
#9. COMPREHENSIVE HEALTH CARE single term (MeSH)
#10. PATIENT CARE TEAM single term (MeSH)
#11. INTERVENTION STUDIES single term (MeSH)
#12. PATIENT CARE PLANNING explode all trees (MeSH)
#13. SELF CARE explode all trees (MeSH)
#14. MODELS NURSING single term (MeSH)
#15. (#4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14)
#16. home
#17. (#15 and #16)
#18. domiciliary
#19. (home next based)
#20. homebased
#21. ((social next support) and home*)
#22. (homecare or (medical next home))
#23. (home and package*)
#24. (outreach and home)
#25. ((alternative next setting*) and home)
#26. (technolog* next depend*)
#27. (home next test*)
#28. (home next visit*)
#29. (home next manag*)
#30. homecare
#31. (home next care)
#32. (home next therap*)
#33. (model* next home*)
#34. (home next program*)
#35. (home next monitor*)
#36. (#18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35)
#37. (#1 or #2 or #3 or #17 or #36)
#38. CHILD explode all trees (MeSH)
#39. CHILD HEALTH SERVICES explode all trees (MeSH)
#40. PEDIATRICS single term (MeSH)
#41. AID TO FAMILIES WITH DEPENDENT CHILDREN single term (MeSH)
#42. CHILD WELFARE single term (MeSH)
#43. CHILD ADVOCACY single term (MeSH)

#44. CHILD CARE explode all trees (MeSH)
#45. PEDIATRIC NURSING single term (MeSH)
#46. (#38 or #39 or #40 or #41 or #42 or #43 or #44 or #45)
#47. teenage*
#48. schoolchild*
#49. pupil*
#50. (school next age*)
#51. preschool
#52. (pre next school)
#53. child*
#54. infant*
#55. babies
#56. baby
#57. adolescent*
#58. (#47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57)
#59. (#58 or #46)
#60. (#37 and #59)
#61. ADULT explode all trees (MeSH)
#62. CHILD explode all trees (MeSH)
#63. (#61 and (not (#61 and #62)))
#64. (#60 and (not #63))

metaRegister of Controlled Trials (mRCT) – via Current Controlled Trials - http://controlled-trials.com/

Searched on 15/02/2007

Retrieved 162 hits

Search strategy

The search interface to this resource is a very simple one and the search had to be modified accordingly. Searched all trial registers except The National Institutes of Health (NIH) –and the NRR. Both these registers are available on other websites with more sophisticated search engines.

Search

(domiciliary OR home* OR homebased OR "social support" OR homecare OR "technology dependent") AND (child or children or Paediatric OR Pediatric OR teenage OR adolescent OR baby OR babies)

Clinical Trials.gov - http://clinicaltrials.gov/

Searched on 09/05/2007

Retrieved 83 hits

Search strategy

The search interface to this resource is a very simple one and the search had to be modified accordingly.

(Search accepted the option to include trials that were no longer recruiting patients)

(domiciliary OR "home based" OR homebased OR "social support" AND home OR homecare OR "medical home" OR home AND package OR outreach AND home OR "alternative setting" AND home OR "technology dependent" OR "home test" OR "home visit" OR "home manage" OR homecare OR "home care" OR "home therapy" OR "model home" OR "home program" OR "home monitor")

retrieved 168 studies

Then "Search within results":

Paediatric OR Pediatric OR teenage OR schoolchild OR pupil OR "school age" OR Preschool OR "pre school" OR child OR infant OR babies OR baby OR adolescent

83 hits

CenterWatch - www.centerwatch.com/ index.html

Searched on 14/05/2007

Retreived 38 hits

Search strategy

Limits: Limited the search to Clinical Trials

The search interface is very basic, so a number of one word/phrase searches were conducted.

Domiciliary -
home based -
homebased -
social support -
homecare -
medical home
home package
outreach -
home test -
home visit -
home manage
homecare -
home care -
home therapy -
model home -
home program

home monitor-

Index to Theses - www.theses.com/

1716- 9th April 2007

Searched on 14/05/2007

Retrieved 35 hits

Search strategy

The search interface to this resource is a very simple one and the search had to be modified accordingly.

(Paediatric OR Pediatric child OR children OR infant* OR babies OR baby OR adolescent* OR teenage) AND (domiciliary OR homecare OR "technology dependent" or "medical home" or "home test" or "home tests" or "home visits" or "home visit" or "home monitoring" or homecare or "home management" or "home managed")

Dissertation Abstracts –wwwlib.umi.com/ dissertations/

Searched on 14/05/2007

Retrieved 47 hits

Search strategy

1 KEY(domiciliary) or KEY(home based) or KEY(homebased)
2 KEY(social support AND home?) or KEY(homecare) or KEY(medical home?)
3 KEY(home? AND package?) or KEY(alternative setting AND home?) or KEY(outreach AND home?)
4 KEY(technology dependent) or KEY(home test?) or KEY(home visit?)
5 KEY(home manag?) or KEY(home care) or KEY(homecare)
6 KEY(home therapy) or KEY(model home?) or KEY(home program?)
7 KEY(home monitor?)
8 #1 or #2 or #3 or #4 or #5 or #6 or #7
9 KEY(Paediatric) or KEY(Pediatric) or KEY(teenage?)
10 KEY(schoolchild?) or KEY(pupil?) or KEY(school age?)
11 KEY(Preschool?) or KEY(pre school?) or KEY(child?)
12 KEY(infant?) or KEY(babies) or KEY(baby)
13 KEY(adolescent?) or KEY(teenage?)
14 #9 or #10 or #11 or #12 or #13
15 #8 and #14 47

ISI Proceedings: Science and Technology – via ISI Web Of Knowledge - http://portal.isiknowledge.com/

Searched on 27/04/2007

Retrieved 237 hits

Search strategy

All lines limited as follows:

DocType=All document types; Language=All languages; Database=STP; Timespan=1990-2007

#1 TS=(domiciliary or "home based" or homebased or ("social support" and home*) or homecare or "medical home" or (home and package*))

#2 TS=((outreach and home*) or ("alternative setting*" and home*) or "technolog* depend*" or "home test*" or "home visit*" or "home manag*")

#3 TS=(homecare or "home care" or "home therap*" or "model* home*" or "home program*" or "home monitor*")

#4 #3 OR #2 OR #1

#5 TS=(Paediatric* or Pediatric* or teenage* or schoolchild* or pupil* or "school age*")

#6 TS=(Preschool or "pre school" or child* or infant* or babies or baby or adolescent*)

#7 #6 OR #5

#8 #7 AND #4

Social Care Online - www.scie-socialcareonline.org.uk/default.asp

Searched on 02/05/2007

Retrieved 382 hits

Search strategy

The search interface to this resource is a very simple one and the search had to be modified accordingly.

@p=("Paediatric*" or "Pediatric*" or "teenage*" or "schoolchild*" or "pupil*" or "school age*" or "preschool*" or "pre school*" or "child*" or "infant*" or "babies" or "baby" or "adolescent*") and @p=("home health care" or "long term home care" or "group homes" or ("process evaluation" and "home") or ("continuing care" and "home") or ("care management" and "home") or ("nursing model*" and "home") or "domiciliary" or "home based" or "homebased" or ("social support" and "home*") or "homecare" or

"medical home" or ("home" and "package*") or ("outreach" and "home") or ("alternative setting*" and "home") or "technolog* depend*" or "home test*" or "home visit*" or "home manag*" or "homecare" or "home care" or "home therap*" or "model* home*" or "home program*" or "home monitor*")

DoH Point - www.dh.gov.uk/ en/ Publicationsandstatistics/ Publications/ PublicationsLibrary/ index.htm

Searched on 14/05/2007

Retrieved 83 hits

Search strategy

The search interface to this resource is a very simple one and the search had to be modified accordingly.

domiciliary OR "home based" OR homebased OR "social support" AND home OR homecare OR "medical home" OR home AND package OR outreach AND home OR "alternative setting" AND home OR "technology dependent" OR "home test" OR "home visit" OR "home manage" OR homecare OR "home care" OR "home therapy" OR "model home" OR "home program" OR "home monitor")

Then "Search within results":

Paediatric OR Pediatric OR teenage OR schoolchild OR pupil OR "school age" OR Preschool OR "pre school" OR child OR infant OR babies OR baby OR adolescent

Appendix 2 Included papers for the trials chapter

1. Bagust A, Haycox A, Sartain S. Economic evaluation of an acute paediatric hospital at home clinical trial. *Archives Disease in Childhood* 2002;87:489-92.

2. Bajaj L, Turner CG, Bothner J. A randomized trial of home oxygen therapy from the emergency department for acute bronchiolitis. *Pediatrics* 2006;117(3):633-40.

3. Braga LW, Da Paz Junior AC, Ylvisaker M. Direct clinician-delivered versus indirect family-supported rehabilitation of children with traumatic brain injury: a randomized controlled trial. *Brain Injury* 2005;19(10):819-31.

4. Gibson E, Medoff-Cooper B, Nuamah IF, Gerdes J, Kirkby S, Greenspan J. Accelerated discharge of low birth weight infants from neonatal intensive care: a randomized, controlled trial. *Journal of Perinatology* 1998;18(6, Part 2):S17-S23.

5. Glueckauf RL, Fritz SP, Ecklund-Johnson EP, Liss HJ, Dages P, Carney P. Videoconferencing-based family counseling for rural teenagers with epilepsy: Phase 1 findings. *Rehabilitation Psychology* 2002;47(1):49-72.

6. Griffiths JD, Martin PR. Clinical- versus home-based treatment formats for children with chronic headache. *British Journal of Health Psychology* 1996;1:151-66.

7. Mattejat R, Hirt BR, Wilken J, Schmidt MH, Remschmidt H. Efficacy of inpatient and home treatment in psychiatrically disturbed children and adolescents: follow-up assessment of the results of a controlled treatment study. *European Child and Adolescent Psychiatry* 2001;10:1 /71-1/79.

8. Maxwell M. RCT of a children's hospital at home service

   In: Register TRF, editor. *Summary Number 921 Retrieved 25 October 2007, from www.ReFer.nhs.uk/ViewRecord.asp?ID=921*, 2002.

9. Morgan G, Craig B, Grant B, Sands A, Doherty N, Casey, F. Home videoconferencing for patients with severe congenital heart disease following discharge. *Congenital Heart Disease* 2008; 3: 317-324.

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Addendum

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton.

Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.

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